

*Report Commissioned by the
State Council on Developmental Disabilities*

**SURVIVING IN THE SYSTEM:
MENTAL RETARDATION
AND THE
RETARDING ENVIRONMENT**

**PREPARED BY:
PEOPLE FIRST OF CALIFORNIA**

JULY 5, 1984

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July 2, 1984

Mr. James Drake
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Dear Mr. Drake:

Thank you for allowing me to see the extraordinary document your organization has prepared. It is a landmark effort for people with mental retardation. It proves quite nicely the lesson that BILL and BILL; ON HIS OWN illustrated. I hope everyone reads it.

I wish you continued success with your noteworthy efforts.

Cordially,


Mickey Rooney

MR:mr

SURVIVING IN THE SYSTEM: MENTAL RETARDATION AND THE RETARDING ENVIRONMENT

This document was prepared by People First of California, Inc. pursuant to Contract #82031 with the State Council on Developmental Disabilities. The policy positions expressed herein are not necessarily consistent with the positions or policies of the State Council, and no endorsement by the State Council should be inferred.

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INTRODUCTION

BACKGROUND OF THIS REPORT

People First of California is a statewide organization of adults with mental retardation who advocate for their own rights both as citizens and as persons with developmental disabilities, and who advocate for the rights of all other developmentally disabled people as well.

There are more than fifteen (15) People First chapters in California, with more than 500 members. People First has strong working relationships as well with a great many non-disabled friends and relatives.

Members of People First live in every imaginable kind of place in which people with mental retardation are found. They live in state hospitals and in community-based residential facilities, both large and small.

Many live in homes of their own, with family, with roommates, or entirely on their own.

The primary objectives of People First are:

1. To assure the availability of services, training, and support needed by persons with developmental disabilities to maintain and increase their capabilities for independent and normal lives, and
2. to demonstrate to the community at large that *persona* with developmental disabilities are PEOPLE FIRST and only secondarily handicapped members of society.

In 1983, People First contracted with the California State Council on Developmental Disabilities to provide the Council with an assessment of unmet needs of persons with developmental disabilities. In the process of performing the needs assessment, People First was also to suggest good ways (a methodology) for getting the maximum direct input from disabled people themselves about what they see as things and services they need.

The contract also asked People First to design a model for helping people with developmental disabilities learn how to organize their own self-advocacy groups and learn how to become personal self-advocates and also leaders of others.

Finally, the contract asked People First to look at the things it learned and the ways it figured out how to involve developmentally disabled people in getting more active in making decisions about their own lives, and put these findings and ideas in the form of recommendations to the public and private agencies and policy-making bodies that have most of the control over how the developmental disabilities service system works.

Some major changes happened in the lives of the People First members who were expected to work on the contract when it was first drawn up.

Because of those changes, the Capitol Chapter of People First, which

is located in Sacramento, agreed to take on the basic work of meeting the contract obligations. The State Council on Developmental Disabilities was very cooperative in extending the time in which to complete the contract and in making other accommodations which helped the special contract "task force" formed by the Capitol Chapter do the job.

A unique thing about this report, and about the way the whole contract was done, is that it truly represents the work of consumers of services of the developmental disabilities service system, and not the work of "professionals". Only one professional was involved in the entire contract project. A non-disabled person with experience *in organizing* and writing reports - but with virtually no experience in issues relating to the developmental disabilities service system - was hired to put the final report on paper. Because of the manner in which the information for the report was gathered, it was possible for the writer to confine his efforts to the kind of work that a combination reporter/editor would do. He did not intrude himself into the information-gathering process except to ask clarifying questions and occasionally to help a task force member to find the words to articulate an idea.

The writer did assist so did the two non-disabled advisors to the task force, with the logistics of moving the task force through the 1500 or so miles it travelled during the twelve days of field trips it made throughout the state. He also visited alone one facility when special opportunity came up.

In all, the task force or sub-groups of it visited about fifteen highly varied living and working places from Sacramento to Los Angeles. About 150 primary and secondary consumers (see definitions), and dozens of service providers and other staff of the places visited, were interviewed with varying degrees of formality. Places visited included state hospitals, large and small community residential facilities, independent living training centers, vocational training facilities, and some unusual programs designed for getting very difficult "cases" out of state hospitals or for reducing or eliminating the need for taking severely disabled people out of their own homes and away from their families.

It needs to be made clear that the task force interviewed only people who are labelled "mentally retarded" or their families, or people who provide services to the "mentally retarded". To be sure, that label covers a very large range of what the developmental disabilities system refers to as "levels of functioning". Many of the people that the task force met realistically cannot be considered candidates for independent living given the existing service system or the existing helping technologies. Others, however, clearly can master the retarding biological impairments that led to their being labelled in the first place. Some have in fact already mastered the biological problems and need only to free themselves from the retarding environment - a phenomenon to which this report will refer again and again.

The group of people who have or can outgrow either or both kinds of retardation - physical and environmental - may in many ways be viewed as proxies for people with developmental disabilities that are not considered as having impaired intellectual functions. In fact, at one state hospital, the task force observed a novel program for hospital residents who have severe hearing impairments. That experience raised a serious question as to whether the labelling of some of those residents as "mentally retarded" related at all to an intellectual disability, or what was being diagnosed" was the reaction to the frustration of being trapped within oneself in a world where other people can communicate freely.

To the extent that this report addresses issues of the retarding environment and suggests ways to overcome it, the audience can be considered to include all persons with developmental disabilities whose "right to be abroad in the land" is impaired essentially by deficiencies outside themselves.

DEFINITIONS

The term developmental disability is defined both in state and federal law. A formal definition is included in Appendix I of this report. For practical purposes, it will be used to refer to a physical impairment such as mental retardation, autism, epilepsy, cerebral palsy and related disorders, to the extent that these impairments interfere with the way people who have them function in society. A person with developmental

disabilities is eligible for certain kinds of public services from the developmental disabilities service system - which includes many, many agencies besides the State Department of Developmental Services and the regional centers - if the qualifying disability happened to the person before the age of 18.

There are many other words that are not a part of everyday speech, or that have been given meanings somewhat or even a great deal different from their everyday meanings, that are used with great frequency by people who are concerned about developmentally disabled persons and the services provided to them. Most of this report is concerned about the living realities of what those special words are supposed to describe. The task force knows very well, however, that these words don't mean the same thing to everyone who uses them. Some of the words - or the use of them - are very controversial. But as long as it is possible to come close to a reasonable and practical agreement on what they mean, it makes communication in a report like this much easier.

The task force decided it wouldn't be helpful to do dictionary-type definitions. Besides what is discussed in this section, wherever it is appropriate throughout the text, an effort will be made, when the special words need to be used, to continue trying to clarify and illustrate their meaning. The task force hopes that by the time people finish studying

even if some of the controversial *words still make some people* uncomfortable.

Consumer

The developmental disabilities system calls people with developmental disabilities who receive services from the system "primary consumers". People who become involved with the system because of the service needs of somebody close to them, such as a son or daughter, or a person for whom they have assumed legal responsibility, are called "secondary consumers".

This report uses the term consumer because it is a convenient shorthand for "person who receive services from the developmental disabilities service system". However, some members of the task force express personal discomfort with the use of the word.

Legend has it that there is a group of people with developmental disabilities somewhere in the eastern part of the United States that refuses to acknowledge the word consumer. Its members call themselves "system survivors".

Some people just can't see themselves as consumers in the sense that a person is who goes into a store to buy a television set. These people say that if that's what is supposed to be meant, then people with developmental disabilities would be able to pick out the kinds of services they want or need or think they would benefit from. Mostly, these critics say, the reality is that people with developmental disabilities are dealt with as if they are things that are worth money. In the television analogy, they view the disabled person not as the consumer of a television set, but as a broken television that has been taken to the repair shop.

The repair person doesn't ask the broken set what is wrong with it, or how it wants to be fixed. Somebody else is the owner, and somebody else pays the repair bill. The television is a thing to stay passive and be worked on. It is valuable to the repair person because money will be paid for the repair service provided.

"But the difficult thing was it seemed like wherever I tried to go, people wanted me for the money instead of myself. They didn't want me for my individuality, but because they knew they were going to be paid to take care of me . . . And the last time I just got fed up and when I found out about the independent living program I said 'I'm going to learn those skills' . . . At first I was skeptical because I thought it would be the same way with them . . . but they didn't want me just for the money and they did give me all the support they could so I could move out on my own and really believe in myself that I could make it . . .

"The last place I lived, when I came back from being away one time they told me they wanted my stuff out . . . and basically they said it was because they weren't being paid enough . . . So ever since I left home I had to worry about somebody being paid to take care of me and that's still the way it is . . . So that's why a job is so important to me, because I'd like to get into a situation where I can say 'Wow, I did something for myself. The state didn't do something for me; they didn't make sure I lived — I made sure I lived.' "

Retarded; Mentally Retarded; Mental Retardation

The first person who used these words to describe people with certain kinds of damage in their brains obviously understood the key concept behind the reality — people who are labelled mentally retarded have sustained some kind of physical injury that has slowed or impeded the rate of growth of their physical, intellectual and/or emotional capabilities.

Two things especially stand out in what the task force heard and observed while looking at services for people labelled as mentally retarded:

1. Far too many of the people who provide services do not seem to distinguish between slow growth and no growth. Even where there is an acknowledgement of growth potential in retarded people, it is all too often accompanied by such low expectations that it isn't even believed when it happens.

Task Force; How soon will you be moving to a place of your own?

Jack (spokesperson for the group of interviewees): Oh, in five years.

Task Force; So long? You seem ready now.

Jack; Well, I was staffed when I asked about it, and they said I'd be ready in five years . . . And they convinced me they were right . . . I'm not ready.

2. At the entrance to one of the state hospitals the task force visited there is a big sign that says in huge letters:

STATE HOSPITAL

and then in tiny letters underneath, as a sort of embarrassed after-thought:

and developmental center

The Lanterman Act pushes the system into the "developmental model of services", which is based on the expectation of growth and therefore on principles which promote growth. The system pushes right back, and defends a stand-still model of no growth. The consequence is the other

delay the advance or progress of"

The task force has had to conclude, from what it saw and heard, that many people are better off for not getting services from institutionalizing and devaluing parts of the system. We also saw clear evidence that people who do get genuine developmental services do better than people who get traditional services. When all other factors are the same, including the type and degree of biological impairment, the evidence seems very strong that the ones who become able to lead the most normal lives are those who have been helped to the greatest extent outside of the traditional service system. In short, the task force suggests a new phrase to be used to sum up the nature and effect of what we have been calling the traditional system of services for the mentally retarded. It is discussed briefly below, and it is discussed in Chapter 2. In keeping with the active meaning of the words being defined in this section, the task force suggests a new phrase to be added to the special list: **THE RETARDING ENVIRONMENT.**

The retarding environment is found in state hospitals, in sheltered workshops, in segregated educational facilities, and often in integrated special education programs. It is found, tragically, in almost every type of program, and even more tragically, in the attitudes of so many of the keepers of the system.

Over and over again, the task force heard how parents can get in the way of the growth of their own children.

"My ~~mom~~ always made a difference between (my sister and me). She always gave my sister her way, and I never got my way. . . . I was in special ed all my life and I didn't like it . . . People would

call out 'You're in special ed — you're retarded' and I didn't like it - everybody made fun of me and made me feel I was different.

". . . I just told my mom 'I'm not retarded!' and I came out of it . . . My sister moved out and I thought about it all the time. And I said 'Mom, I'm moving . . .' and my mom said 'Oh, wow!'

"My adult school counselor said 'You can't go get a job' - and I just went and did it. I told him 'I can do it even if you put me down' — and I did it . . . At that school there's a lot of people who act like they're retarded, and I said 'I'm not like that' and I grew out of being retarded."

Normalization; Cultural Valuation and Devaluation; Social Integration and Segregation; Deinstitutionalization and Institutionalization

The group of words above refer to good and bad life experiences of people with developmental disabilities, and represent ideas that are very important to people who believe in what the Lanterman Act set out to accomplish. Because these words all interrelate and interact meaningfully, they often are used to define each other. It is much easier and more useful to talk about them together than to try to use dictionary definitions.

The very first section of the Lanterman Act, Section 4500 of the California Welfare and Institutions Code, says:

" . . . Services should be available to enable persons with developmental disabilities to approximate the pattern of everyday living available to nondisabled people of the same age."

Toward the end of the Act, Section 4830 says:

" . . . 'normalization' means making available programs, methods and titles which are culturally normative and patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society."

"Culturally normative titles" may seem a little confusing. The task force believes it means "Don't call a man a 'boy' or a woman a 'girl' or a group of adults 'the kids'." There will be more to say about that later in the report.

The idea, the concept behind normalization, whether or not the word is the best choice that could have been made, goes far beyond the mere definitions in the law. Primary consumers talking about their own lives help provide some feeling for the goals and meanings intended by people who believe in normalization:

". . . In the last year of high school, you know, they take you on a trip . . . So this teacher says 'I want to put your name down.' But I say 'I can't, my mom won't let me go.' . . . So the teacher says 'Ask anyway . . . there's nothing to lose.' I went home and I explained to my mom that I want to go to a trip, it's my last year and I want to go to a trip with everybody, and they're all going together, and my mom just looked at me and said 'NO'. And I said 'Mother, this is my last year and I want to go to a trip with everybody.' 'NO.' 'Could you give me a good reason?' 'No. You're gonna get lost and all that, and I don't want to hear any more.'

". . . I want to go so bad I'm sick in bed — really sick. That teacher came all the way to the place where I lived to talk to my mom — everybody signed a card and they want me back, they want me to go to the trip - and she came and talked to my mother . . . I was really sick because I wanted to go SO BAD . . . and the teacher went to the kitchen and I heard her say 'I'll be responsible.'

". . . I was so excited. My mom took me to town and bought me an outfit to wear . . . My mom and dad take me and wait till I get on the bus and I said to myself 'The teacher is going to watch me just like they do in Sunday school . . . she's going to be my shadow . . . What she did was, I get off the bus and she says 'You go along with the others and have fun and enjoy.' I didn't know what to do — I just, WENT — I feel like a BIRD — the first time of independent living, of freedom, and I LOVED IT. We went to the sand . . . and I take my shoes off and I RUN. I mean I run in the sand, in the water — I didn't want to come home."

Years later, this same person went to live on her own, and joined People First:

". . . My mom says 'Who's more important, these new friends of yours or me?' And I say 'Mother, I love you but they're important . . . because it's time for me to be able to help some people . . . because somebody helped me — people who touched my life and helped me to grow

". . . I was wasting my life being bitter . . . I remember the first time I go into town and somebody says my slip is showing and I cried -- I was that sensitive, you know? Now somebody can say it and I can say 'Pretty slip, huh?' and go on from there — it doesn't bother me . . . And now I want to touch people and help them understand they have rights. Some people don't think, don't know they have rights . . . (Other people with developmental disabilities) are very precious to me because once I thought I was the only imperfect human being in the world, I really did."

Outside the intensive care medical ward at a state hospital:

". . . They told me that if I had been born ten years before I was born I wouldn't have lived. There were a whole lot of years in my life, when I was growing up at home, when I was in the state hospital, when I was bounced around from residence to residence and it seemed nobody wanted me, that I often wished I had died instead of living the way I was. But now I've learned that there are people who care for me because I'm me, and I've learned how to do things for myself and live on my own, and I feel I'm somebody. . . And I'm independent enough now that I want to be able to help other people, so now I'm glad I lived."

Some people believe it is easier to understand the goals that underlie laws such as the Lanterman Act if you try to see ways that people act or are acted upon in terms of what a society or a culture values or devalues.

When a person with mental retardation is turned down for counseling for emotional problems by a local mental health program because the intake worker doesn't believe that you can have emotional problems if you're retarded, that program or that worker is being allowed to devalue retarded people.

To be a Boy Scout may be a culturally valued status for a twelve-year old; to be made a Boy Scout at age 35 is a form of cultural devaluation, because it designates a man as a child.

When people with mental retardation are taken to the movies or bowling in large groups, even though they are participating in normal community activities, they are being subjected to devalued treatment by being exposed to the community in a way that makes ordinary citizens think that developmentally disabled people "have to be herded around like that."

The experience of being devalued goes hand in hand with being segregated from positive interaction with nondisabled people in ordinary social settings, with being managed like a piece of property or a unit of livestock — in short, being institutionalized.

The following dialogue took place at a residential facility between Mr. X, who is about 40 years old, and various members of the task force, including a secondary consumer:

Mr. X; At this home the employees are in charge of you and they've got to know where you are at all times . . . so you sign out when you go anywhere, even for a walk The staff keeps your (personal and incidental Supplemental Security Income) money for you to keep it safe

Task Force: Suppose, when you sign out, you ask for \$5 of your money to go to the movies. Is there anybody that says NO?

Mr. X; Yes, if you did something wrong . . . Suppose I hit another kid . . . they can put punishment on me — they can say you can't go downtown for a month.

Task Force: People who are developmentally disabled have traditionally been seen as unable to think for themselves and speak for themselves. And so parents, or teachers, or counselors, or the government have made decisions for you. They've made the decisions and said "That is the way your life will be. If you live in a residential facility, you will go to a day program every day" . . . or maybe "You will go to church every Sunday" or "You will go to bed at 9 o'clock every night and you will get up at 7 o'clock every morning" — maybe you get a key to your room and maybe you don't — all these kinds of rules that most citizens of the United States do not get put on them . . . especially after they reach the age of 18.

The task force encountered many examples of punishment — most frequently confinement of one sort or another. It did not, however, encounter a single person with developmental disabilities who was aware that the kind of punishment might be unconstitutional or that even if it might be permissible under the law to impose some kinds of restrictions on people, the Lanterman Act is very clear that any abridgement of rights of a person with developmental disabilities must be documented and justified and reported to the Director of the Department of Developmental Services (Welfare and Institutions Code Section 4504).

Developmentally disabled people can break out of a devalued, institutionalizing, non-normalizing, segregated, retarding environment. But why should they be trapped that way in the first place?

Manager of an on-the-job training program; " . . . You don't throw people who have limited social experience together with other people who have limited social experience and expect them to "act right". They won't know how . . . I heard of a program . . . that works with a university with students that need the money, and it says:

" 'We'll pay your room rent (which is a couple of hundred dollars a month) and you will be a roommate to a person (with developmental disabilities). These are the requirements — you must make sure you participate together in two social activities a week, and that you have dinner together at least three times a week' and that sort of thing . . . • And they have the college kids lined up to sign on . . . And so they learn how to act when girls are around, and when this or that happens . . . and the student is having experiences just as valuable as the disabled person is . . . Now isn't that better than 'Now this sheltered workshop is going to have a class in socialization . . . everybody meet in room seven for socialization class' "

Independence

Independence is a word that probably brings up more positive and hopeful feelings to people with developmental disabilities than any other word — except perhaps the words "you're hired".

In a civilization like the one we all live in, nobody is independent in the sense of not needing the good will and services of other people. The idea of independence in the context of developmental disabilities revolves around how much control a person has over the things that go on in his or her life. To repeat a very powerful statement made by a person with severe physical handicaps:

". . . I'd like to get into a situation where I can say: 'Wow, I did something for myself. The state didn't do something for me; they didn't make sure I lived. I made sure I lived.' "

Depending on the life situation they're in, primary consumers frequently see independence as bits of knowledge and activity that nondisabled adults rarely even think about:

Independence means I can turn on my stereo and just listen to it anytime.

Independence means to know you have to pay your bills.

Independence means to be able to go somewhere and make new friends.

Independence means to know how to take the right bus where you want to go.

Independence means a room all to yourself.

Independence means a regular job at regular pay.

Independence means I don't have to ask my conservator if I can visit my brother and his family for Christinas - and get told NO.

Disabled members of the task force have drawn great strength from each other - that is one of the reasons for organizations like People First. But part of that strength comes from knowing that the relationships are freely entered and can be freely ended. As much as task force members need each other, they know that about the last thing any of them needs is to be with the others all the time.

Most adults have a relatively large degree of choice of people with whom they want to associate - at least away from work or school. They have a relatively free choice of what to eat and when, what recreational activities to engage in, if any, and when. They go to bed when they want to. When these common matters of choice are curtailed by institutionalization, people can **lose** or appear to lose the ability to function independently when opportunities do present themselves.

People who operate independent living training programs are quick to say that the need is as much to help people recover from the effects of having been kept psychologically dependent as it is to teach them the practical skills of living on their own.

Task Force; Do you have a resident council to work on getting changes in the rules you don't like?

Group Leader; We did it once, but nobody came. The administrator says "If the residents don't like certain rules . . . why don't you get a committee started?" . . • and nobody came.

Task Force; Why?

Group Leader; They're afraid the staff will come down and punish them . . . A staff member came to that meeting and they all just stared . . . and the staff person got tired of it. Then they all go outside and bitch — 24 hours a day. So what can you do with people who won't do anything for themselves?

**PART ONE:
UNMET NEEDS ASSESSMENT**

CHAPTER 1:
INTRODUCTION AND METHODOLOGY

CHAPTER 1:

INTRODUCTION AND METHODOLOGY

When People First made the agreement to do this report, it accepted the responsibility for doing an assessment of the unmet needs of service consumers in the developmental disabilities service system. At the same time this needs assessment was being done, People First would also work out what it believed to be the best ways (methodology) of getting consumers to participate as fully as possible in the process of identifying their unmet service needs.

At the beginning the task force looked at formal questionnaires and thought about developing its own. However, the conclusion was quickly reached that this could not be a "scientific" study in the sense of gathering large amounts of data in a standards format and then doing statistical analyses of that data. The task force simply didn't have enough time, money or expertise to do that. It was decided that meeting with groups of consumers and working out ways of getting them to talk freely and informally was the only possibility for answering both needs assessment requirements.

The method of collecting the information was to audio-tape the meetings. The task force collected about 60 or 70 hours of such tapes. Because of collecting data this way, much of this report can be written by letting people speak for themselves through transcriptions from the tapes.

[EDITOR'S NOTE: Every effort has been made to suppress the identity of the people who are quoted, where their clearance was not expressly given. Editing of the transcripts has included some paraphrasing where necessary for clarity, but the truly dramatic statements have been left in the words of the people who said them. Possible identifying characteristics of people or places have been randomly altered to enhance confidentiality. No fabrications have been intruded.]

The methods to get responses on unmet needs from the consumers had some expected results, and some surprising ones. When specific areas of service needs were brought up, such as residential situations, vocational training, transportation, health care, education, etc., most of the responses fit into the same kind of "laundry list" that unmet needs assessors in the developmental disabilities system encounter over and over again. A condensed list of these concerns is included in the appendix.

However, in general discussion, when people didn't feel on the spot to answer direct questions, a great deal of information came out that bears more fundamentally on how the system operates. Those conversations, as distinguished from the more formal interrogations, when reviewed later in the context of the entire information-gathering process, led to a decision to examine some of the broad, more serious issues in the main text in a way that may be most productive, if non-traditional.

Methodology

The best response the task force can make to the requirement to develop a methodology for getting consumer input to a needs assessment is to describe what the task force itself did, and some ideas about why things turned out as they did.

1. The task force, insofar as possible, went to where the people who were to be interviewed were. If that was not possible, the most informal, homelike, neutral settings was arranged. The people who were being interviewed, therefore, didn't have to deal with the distraction of strange or threatening surroundings.
2. The task force always went through an initial phase of telling the people why it was there, explaining briefly about the contract with the Council, and explaining what is meant by "unmet service needs". Each task force member would tell a little bit about himself or herself, and each member of the interview group was invited to do the same. If people were shy and didn't want to talk, they were assured that that was fine, and they were reminded that any time they did feel like talking, their comments would be welcome. When an interesting exchange got going, on or off the subject, it was encouraged as part of the general "ice-breaking" and soothing first part of the meeting. In every case, too, the principle of confidentiality was explained in asking permission to tape the interviews. (In only one situation, with a service provider, was there resistance to taping, but after everybody got acquainted and comfortable with each other, permission was granted.)

3. Wherever the set-up allowed it, the task force made sure there was a lengthy lunch or refreshment break to allow individuals to get to know each other on a one-to-one basis. This made it possible for shy people to ask questions that they didn't want to ask in a big meeting, to ask and answer personal questions and perhaps even discover mutual acquaintances — in other words, to get rid of more "strangeness" that couldn't be handled in the regular meeting.
4. Except for a few individuals who just weren't able to overcome their shyness or fear in so short a time, the second part of the meeting generally brought out a much deeper and freer type of communication, much more informative of reality. Some of this happened because of the rapidity with which genuine closeness was observed to develop between consumers who had been strangers a short while before. Part of it happened because consumers work very hard at helping each other communicate, especially when language problems are difficult. It is a matter of genuine empathy on the one hand, and the absence of the tendency frequently found when non-consumers work with consumers — namely the tendency of the more articulate person to "put words in the mouth" of the person having difficulty expressing herself or himself.
5. It was most often during this latter part of the meeting that the interviewees began to realize that disabled members of the task force were system survivors, having taken the worst the system could dish out and having made use of the best there was to take advantage of, and having become remarkably independent and normalized in the process. As a result, what seemed to have started out as a kind

of funny visit of a strange, almost rag-tag crew - especially where the host group was a bunch of "superstars" of the independent living training system - often ended with the interviewees interviewing the interviewers about what they had done right or what somebody had done right on their behalf.

The task force, therefore, through the character-building experiences of its members and through the remarkable way it fit together as a group, seemed to represent a symbol of a possible future for the people being interviewed. In a sense, the task force had turned into the embodiment of the self-advocacy model it was charged with designing. More of this exceptional phenomenon will be discussed in the chapter on self-advocacy.

**CHAPTER 2:
THE RETARDING ENVIRONMENT**

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The single, most widespread and alarming unmet need that the task force identified was the failure of large numbers of service providers to understand the law and the principles behind it - and consequently, their failure to operate in accordance with either.

That this is not universally the case, that there are some glowing exceptions out there in the real world, only intensifies the distress caused by this finding.

By and large, the feeling in residential care facilities, from the largest to the smallest, in state hospitals and community care facilities, in educational and vocational training facilities and programs for the developmentally disabled, and in general, wherever the "keepers" and the "cared for" are found — the feeling forms the background and the backbone of what the task force has come to call "the retarding environment".

- There is an overwhelming bias toward dealing with people labelled mentally retarded as if they are children. This rubs off on consumers and they think of themselves and refer to themselves as "boys and girls" or as "the kids".
- At one facility there is an official troop of the Boy Scouts of America. Its members are men and women ranging in age from their 20's to their 50's.
- The most common item of personal property in evidence in state hospital living quarters is stuffed toys.
- At one facility, independent living trainees mentioned proudly that they had telephones in their rooms. Later in the conversation one of the trainees was asked if the 911 number was

in effect in that community, or who should be called in the event of a fire or like emergency. The answer was "We're not supposed to decide what's an emergency . . . We're supposed to call a social worker."

- I'm currently involved in a sheltered workshop . . . which is putting me down the tubes They really don't make you normalized, they make you more retarded You get a whole bunch of mentally retarded people and they just copy off each other on how they're supposed to act, and instead of going uphill out of retardation they go downhill being more mentally retarded . . . I see that every day.

- Task Force: Do you go to the movies?

Interviewee: Oh, yes, we do on the weekends. We have a weekend program which is very exciting.

Task Force: How many people go with you, or do you go alone?

Interviewee: It varies - as many as 25 people on the list if they've been good . . . sometimes 10 We mostly go in groups because even if it's safe in the day something bad could happen.

- The task force is visiting a workshop, where one of the supervisors is explaining earnestly and sweetly how the trainees learn how to make ceramic butterflies for wind chimes. A trainee in a wheelchair, who obviously has a problem and considerable difficulty in explaining it, interrupts the supervisor's presentation. The supervisor snaps at the trainee "You've been a pain in the neck all day — now go be a pain in the neck by yourself!" — grabs the wheelchair and shoves it across the room into a wall, where the trainee ends up facing the wall and unable to move. The supervisor turns back to the task force and sweetly resumes the presentation.

The pervasiveness of these experiences at so many of the places the task force visited cannot be explained by a statement that the developmental disabilities system is run by bad people. To say that would be both inaccurate and unfair. Some of the most distressing examples of how not to foster growth and development were, however, the work of clearly

dedicated and well-meaning people. There may be more than a little truth in a statement that seemed grotesque at the time the task force heard it, because it was uttered by a person who was clearly in the clutches of the retarding environment:

We know the staff here loves us. They wouldn't be here if they didn't.

The situation could be improved immeasurably if the basic understanding of the nature of the retarding environment could be brought into the consciousness of both service providers and consumers. In view of the related finding that so many service providers do not seem to understand the law or the principles behind it, the task force makes the following recommendations to the California Legislature:

1. The Legislature should require every service provider in the developmental disabilities system to graduate from an approved course of instruction and training in the content and objectives of the Lanterman Act and related laws, including federal and state constitutional protections of citizens. All employees, public and private, of the developmental disabilities system and closely related service systems would be covered by the requirement. The curriculum of such a course should be put together by qualified professionals in education, and these professionals should be advised and supervised by a panel of judges, members of the Legislature, and the State Council on Developmental Disabilities. The same training should be made available for members of area boards and members of the State Council.

2. The Legislature should appropriate funds or require the State Council on Developmental Disabilities to set aside funds to develop a clear and understandable explanation of the Lanterman Act and related laws and constitutional provisions of importance to consumers of services in the developmental disabilities system. Whatever communications devices are appropriate should be used, including written and illustrated materials, audio and/or video productions. Consumers should be fully involved in the preparation of such materials. Coverage should include specific highlighting of the legal rights and responsibilities of consumers, the legal responsibilities of service providers and advocacy panels established by law, outcome objectives of service programs, and how consumers can find help to resolve problems if they have reason to believe the system is doing something wrong or is failing to do something required by law.

The California Legislature has been working on legislation to get the developmental service system to establish much more precise and accountable standards on a statewide basis for licensing, accounting procedures, and most of all good quality programs of service, as recommended by the State Council on Developmental Disabilities. Legislation like this is strongly supported by People First. The chances of such stronger laws working would be greatly enhanced, we believe, if the kind of training for providers and consumers suggested above were also required.

**CHAPTER 3:
THE FATE OF THE
STATE HOSPITAL SYSTEM**

CHAPTER 3: THE FATE OF THE STATE HOSPITAL SYSTEM

When the task force began the work that led to this report, there were perhaps as many members as not who sincerely accepted the principle that there would probably always be a need for a state hospital system to back up the community-based service system for people with developmental disabilities. However, by the time the writing stage of the report had been reached, not a single member of the task force was willing to defend that position.

A unanimous opinion of the task force is that, except for Penal Code commitments, which the task force simply isn't prepared to deal with, there appears to be no programmatic or service-based justification for any long-term plan for serving people with developmental disabilities that would include preserving the state hospital system.

The report of the Assembly Office of Research (see Appendix III, pp. 78-79) quotes the director of one state hospital:

"Regional centers often refer clients (to a state hospital) with a justification that the state hospital is the only available alternative . . . 'availability' has no place in an admission decision . . . we still have clients who are quite eligible for community placement, and whose families do not object to community placement, who cannot be accommodated. Some regional centers have slacked off on placement activity because of what they perceive as insoluble budgetary constraints or resource development problems. We have continually turned down many individuals for admission who are much closer to being eligible than several hundred of our current residents"

The Assembly Office of Research report then goes on to say (p. 79):

"State hospital populations include greater proportions of people with complex behavioral problems and people requiring continued medical care. Nonetheless, many people with developmental, medical, and behavioral problems similar to those who live in state hospitals can be served successfully in effective community programs. . . ." (Emphasis added)

The report then describes the successful phasing out of the program for people with developmental disabilities at Patton State Hospital in California, and a community-based program in Michigan, two examples which clearly illustrate the fact that "state hospitals do not . . . function to meet the needs of a unique population by providing a unique service model; rather, state hospitals function to make up for the deficiencies of communities." (P. 83, emphasis in original.)

The task force knows about successful test situations in which people who have to be kept alive with tubes in their tracheas for breathing, tubes in their stomachs for feeding, who need to be monitored constantly to be kept alive, are being cared for in home-like environments that cost less than a tenth of what the care in a state hospital costs for the same people.

A task force member visited a community treatment program that provides a home-like environment for people who were originally put in state hospitals under the Welfare and Institutions Code provisions dealing with individuals who are deemed to be a "danger to self or others", or because they have been diagnosed as autistic. The program has been overwhelmingly successful in reducing or eliminating people's troubled behavior - since its inception

in California more than a year ago (and during the several years it has been operating in other states) it has never had to return a client to a state hospital. Medication has been drastically reduced in many cases. Costs are substantially below state hospital costs for the same kinds of patients.

The task force talked to the mother of a long-time state hospital resident. Her plea was not to recommend closing of the hospital where her

to run away, and the mother didn't want her to have to go through that experience again, out of sincere compassion (although perhaps faulty understanding of why the patient kept trying to run away). When told about a program (see Chapter 10) that helps parents learn how to manage children with the same problems and get services in the community to keep them at home, this same mother had the courage and self-possession to be able to say "Perhaps if I'd have learned about such things years ago, my *child's life would have* been very different."

The task force members who spoke with this woman felt a real sense of grief that they weren't able to assure her that it would still be possible to make a difference in her daughter's life -- because no one felt it was fair to hold out the hope of promises that so far have not been kept very well. Perhaps if some of the things this report says should be done - or should be stopped - are attended to, that mother and many like her can be enlisted in a much more positive effort than working to keep state hospitals open. The task force understand that 59 percent of the dollars

available for services to people with developmental disabilities in California go to care for the 11 percent of the disabled population that is being kept in state hospitals. How much more service - and hope - that money could buy on the outside, given what is known about doing things right.

For example, the town of Porterville, which probably stays alive economically because of the state hospital, is also the home of some outstanding community programs. It also boasts a large population of people who are or who, with proper training, could become, some of the best service providers in the country. Imagine how a town like Porterville, with intelligent planning, timing and dedicated help from Sacramento, could truly prosper by turning into a model of community service and deinstitutionalization.

Clear and sound ideas for developing such a transitional program to a fully community-based one can be found in the California Developmental Disabilities State Plan and legislation introduced into the California Legislature. One idea is selling off or renting state hospital buildings and lands — which apparently are worth between half a billion and one billion dollars on today's market — and using the proceeds to finance the development and improvement of services outside the hospitals. Ideas like this have the unqualified support of People First.

The task force does not mean to imply that it believes an end to the state hospital system would assure in any short term an end to insti-

tutionalization in the negative, retarding environment sense of the word. But it is hard to believe, having seen some of the best state hospitals, that any good can be achieved in them that can't be achieved better, faster, and more cheaply in a less restricting, less institutionalizing, less retarding environment. Community care has a long way to go to keep the promise of the Lanterman Act, but there is a clear prospect of achieving such goals in the community. There is no such prospect for the state hospitals. CLOSE THEM.

**CHAPTER 4:
THE GENERATION GAP**

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THE GENERATION GAP

In reviewing what consumers had said during interviews, and in looking back on what had been observed, the task force began to realize that there were certain kinds of needs that related mostly to the life experiences of people within a changing service system. This realization may be most easily expressed as "the generation gap" because by and large people in certain age groups have had various kinds of experiences with the service system that other age groups may not have had because the system has changed the way it does things.

The task force believes that this way of looking at things may help people understand some of the issues more clearly, and may help policy-makers figure out how to make service providers focus resources so that they are more on target and have better results.

It should also be noted that on the whole the changes that have come have been positive. Unfortunately, it has been necessary to talk mostly about negative things in writing this report, because the job has been to identify things that need to be improved. Also, in developing a "self-advocacy" model, the task force found itself dealing with such issues as confrontation and self-assertiveness, which tends to create a state of mind that sees an enemy or an oppressor on the other side.

The reality is that if things weren't changing for the better, there would be no State Council on Developmental Disabilities that has the good judgement and courage to negotiate a contract with a group of people labelled as mentally retarded. Whatever else may be said in criticism

of the developmental disabilities service system, its willingness to ask for evaluation by its own clients says something very good about where things are - and can be - going.

The Past

During a visit to a state hospital, the task force met a man who remembered being kept in a dark basement when he was a child. That man is now in his sixties. It is not unfair to argue that there probably was a long period in his life when he was better off in a state hospital - if the only choice was between being locked in that dark basement by his parents or being forgotten on the back wards by the state. It is also fair to note that he was included in the group of people who met with the task force and were free to say what they wanted.

On the other hand, it is a realistic prospect that the same man would have a very difficult experience trying to adjust to life outside the hospital after all these years inside. That is no excuse for maintaining the state hospital system, as some people argue. It is, however, a very strong challenge to the developmental disabilities service system to develop adequate community-based services for lifelong clients who may not have been assisted to prepare for the freedom of a deinstitutionalized environment.

The service need in such cases is to find ways of cleaning up past errors of the system. The effort to do this is not likely to be of any relevance to the children now being born with developmental disabilities,

if they are going to be brought up in a non-institutional service system, as they should. How much relevance it has to the needs of the large middle generation which has experienced such a wide variety of treatments is a very hard question, but one which the system must try to sort out.

The Future

One member of the task force might have been written off twenty years ago as "hopelessly retarded" except for his mother's refusal to accept the official judgement of the system as it existed then. Today, that young man is in many ways the most normal, most normalized member of the task force. He drives a car. He has a real job, and is currently applying for a better one. He lives in his own apartment with a non-disabled roommate of his choice. His social life involves as many or more non-disabled people than people with disabilities - an uncommon experience even of most developmentally disabled people who are living on their own.

This young man has biological impairments that will always be a cause of his having to live parts of his life differently from people who don't have such impairments. But he will never know the hopelessness and helplessness imposed by the institutional system of services for people with mental retardation. He is a living yardstick, compared with people of his own age group who have been subject to that system, of how much "retardation" is in fact the product of the system itself.

What this man's family did on his behalf, and what they didn't let the developmental disabilities system do, may represent the pattern of services that needs to be provided to generations to come. More of this will be discussed in the chapter on "success stories".

The Present

The hopeless/helpless syndrome has been part of the experience of most members of the task force. They are still fighting their way out, and probably their lives and their view of the world will always be affected by it, even when they have achieved true social integration and economic independence. They represent the significant "middle generation" of people for whom changes for the better in the developmental disabilities service system cannot come too soon, and for whom they need not come too late. The largest part of this report is really devoted to the unmet service needs of this generation.

One of the promising developments for people in this middle generation is the rise and growth of independent living training programs. As positive - as this movement is, it is a fact that its very existence puts some old problems in a new light and, to some extent, it even creates new problems that have not been a matter of concern in the past. It is urgent to look at these problems.

As increasing numbers of people with mental retardation and other developmental disabilities graduate from independent living programs, the realization begins to dawn that being able to manage one's own life away

from the "keepers" does not in and of itself assure an end to segregation or social isolation. As a matter of fact, being able to live without supervision because you have learned to keep yourself and your apartment clean and presentable, because you know the importance of paying your bills, because you can cook for yourself and use public transportation by yourself, and in general manage your own affairs, can bring with it the shocking realization, when you're out there alone: "My god, now what do I do with my life? Is this what it's all about?"

If you've had enough of the institutional and institutionalizing system, the retarding environment, and you've rejected further "training" in a sheltered workshop or further "education" in a segregated adult school, and you don't have a job or a good training program to go to, if you still have learning disabilities that make regular school settings uncomfortable or unrewarding, what do you do?

Also, at this point, the weaknesses of the public transportation system become a new kind of oppression. What good is it to be able to know how to take the bus to the shopping center or to the movies, if the buses have stopped running by the time you're ready to come home?

At this point, too, what used to be painful but perhaps distant or avoidable concerns about the general public's lack of understanding about people with developmental disabilities can become a daily reminder of the awful feeling some people went through all too often in special education classes.

A young woman with Downs' Syndrome bursts into tears when her colleagues rebuke her for missing an important meeting. "Sometimes," she explains when she has regained control of her emotions, "I just can't make myself take the bus because it hurts so much when nobody will sit down beside me."

There are no easy solutions to this emerging set of problems. Government has been trying to improve public transit in general and special transportation programs for the handicapped in particular, with mixed but usually not outstanding success. Committees and organizations to find suitable alternatives to traditional work and training programs for disabled people are not in short supply - but the alternatives they are looking for are in short supply-

There is reason to believe that as more developmentally disabled people find their way into the mainstream of society, the public will abandon its traditional misunderstandings and hostilities. Positive educational efforts by private organizations and government can and do help this

Perhaps what is most important at this time for both consumers in transition and for programs that assist in this transition is to sharpen their awareness of the problems and pitfalls. For example, one excellent independent living program the task force visited would not let people graduate until they had learned how to link up with an organized group of non-disabled people, such as the YMCA or Sierra Club, or even the Audubon Society. This might not be a perfect way to achieve social integration, but it is a good start and an important statement.

Perhaps it is time for independent living programs to tie in with driver training programs, since the emergence of a few thousand more people from institutional isolation isn't going to make the magic that reforms the public transportation system. Perhaps just a lot more brainstorming about how to help people who can't drive get around, and about tying up with groups of citizens who might add their weight to the helping effort, is needed.

Summary Restatement of Generation Gap Issues

Because this way of looking at unmet service needs puts the issues in a novel framework, it seems worthwhile to review and restate the analysis:

1. There are people being served by the developmental disabilities service system, mostly older people, who have been so institutionalized (and perhaps, before that, so brutalized), that it is very difficult to habilitate them to less restrictive environments. That is no excuse for not trying, and no excuse for keeping the state hospital system in existence. The developmental disabilities service system has a very deep responsibility to provide services for this population to meet the deinstitutionalization objectives of the Lanterman Act.
2. There is a large population of people with developmental disabilities who are generally young and/or flexible enough that the effects of the retarding environment on them to date can be overcome with genuine deinstitutionalizing and normalizing support from the service system, from their own peers, and from the community at large.

The People First task force is a mixture of such people, and it also contains a representative of what ought to be the wave of the future.

3. The third group is composed of a relatively few people who have escaped virtually all of the impeding effects of the retarding environment, and who, in their ability to function in the world show what is possible when things are done right. What has been done for this group, and what has not been done to them, may be one of the best models of how the developmental disabilities system should approach the developmentally disabled young children and infants of today, and those that will be born in the foreseeable future.

**CHAPTER 5:
GETTING THE MARKET
TO CREATE MORE AND
BETTER SERVICES**

CHAPTER 5: GETTING THE MARKET TO CREATE MORE AND BETTER SERVICES

The Lanterman Act had anticipated that free market forces would lead to the establishment of more and better services for people with developmental disabilities. But the reality is that more than 600 people who are ready to leave state hospitals for community services are still being kept in hospitals because there's no place for them to go. As bad, or even worse, is the fact that more than 250 more people have been sent to state hospitals between July 1983 and April 1984, for no other reason than there were no community facilities in which to house them.

The task force encountered an example of how mixed up things are in the present system. Despite the unanimous recommendation to end the state hospital system, the task force knows a good program when it sees one, and one of the best encountered is based at a state hospital. This is a "total communications" program for people with impaired hearing, and also for people who can hear but haven't learned to speak.

This program has had some success in placing people in the community, but it keeps getting referrals from all over the state of people who need the service, so in effect people are being placed in state hospitals just because that's where the good program is located.

. . . (The clients) knew what they wanted to say, but they couldn't get it out. They also knew that people had low expectations of them and they were frustrated by that. And so in about two-and-a-half years after we started we had a group of about 35 residents who were ready to go . . . (these were people who) had gone from about zero to a hundred in that time And we looked around and there was nothing out there for them to go to. And we worked with the regional centers and the area board, and (a private organization for the hearing-impaired) . . . and they helped and we got a place going in (one community). We call that the "State Hospital Annex" because once they got opened we almost placed that whole first group, as a group, in that community facility

. . . They're looking now, and most of them just have that place as a home base We've assisted in getting several other community facilities organized, (but for the most part they're just not putting together) real support programs for the hearing- and speech-impaired in the community

. . . We're not geniuses here - we've figured out over the years what to do for this group of people, but anybody else could do it too At the beginning, approximately one-third of the people we worked with didn't have hearing impairments but had never developed speech, and they did beautifully too in the program. They were easier to place in the community. Hearing people's speech actually improves when they learn another form of communication. In some cases, the clarity of speech didn't improve that much . . . but just the reduction of frustration made a big difference in their ability to relate to the world

. . . (Now we don't work with people who don't have speech but aren't hearing impaired, because) once this program became known we got placements of the deaf from all over the state, so we can't work with hearing people the way we did.

People First believes that every parent or guardian of every hearing-impaired person who is also labelled mentally retarded, and every parent or guardian of any person who is not hearing impaired but cannot speak, should know about that program and more important, about what can be done for people with those disabilities. Then these secondary consumers, joined by all those primary consumers who were helped to escape from the retarding environment by that kind of help, should set up a scream that will be heard in Sacramento and Washington for the establishment of such

programs in every major community. What kind of sense does it make to put people in state hospitals just to receive a service that could benefit hundreds or thousands if it were available outside? What kind of sense does it make to accept admissions from "all over the state" when the program isn't adequately supported to provide service to the non-hearing-impaired who are already in that hospital?

One piece of California legislation even goes so far as to propose to make:

" . . . no-interest start-up loans to non-profit organizations or agencies that wish to provide quality residential or non-residential services to people who currently reside in large state or private institutions, or who are at risk of such placement. Loans for this purpose shall be made specifically available to qualified state hospital employees who may wish to start community-based programs." (Assembly Bill 3811, Stirling, as introduced in 1984.)

If such legislation were enacted, the staff of that hospital-based program ought to get out into the real world and make waves and make money. Non-profit or not, if anybody ever deserved to get rich, it's people like the staff of that program.

The task force believes there are two related problems in stimulating a market-based expansion of community care. First of all, the amount of money available to attract first-class services is not available because it is trapped in the state hospital system. The really good community programs, independent living training, home and family assistance programs, *are being* underfunded in a classic penny-wise, pound-foolish way *by* regional centers - mostly because they just haven't got the money, or

are under strong pressure to continue giving it to the traditional care providers, whether those services are any good or not.

Second, the way reimbursement is made to providers does not contain any incentives for doing a better job. In fact, the current system makes it possible for providers to make more money by holding people back. The "higher functioning" the individual, the lower the reimbursement to the care facility. And so the task force ran into example after example of people who were being told they weren't "ready" for independent living, when in fact many of them were "higher functioning" in some ways than members of the task force, all of whom live independently.

The conclusion is inescapable that successful services are rare because success is not rewarded. Maintaining the retarding environment pays better.

Nevertheless, the hopes of the Lanterman Act for getting the free market to operate in the public interest should not be abandoned. We are in a sorry state if people who know how to build a better mousetrap look out the window and see the government planting land-mines in the path to their door. There is an overwhelming need for developing reimbursement systems that make significant rewards to service providers who consistently achieve measurable, desirable outcomes.

Perhaps this effort needs more consumer involvement. Perhaps the system will get better at specifying desired outcomes if it follows up on our recommendation to collect and evaluate real-life "success stories" (see Chapter 8).

California law requires minimum quality standards to be developed by the system. That still hasn't been done. The Legislature must continue to do whatever is necessary to make that law be implemented. The state must stop paying for services that aren't any good while it starves services that will save it millions. To continue the present upside-down system is to show the people government at its worst and most impotent. We think our elected officials are capable of better.

**CHAPTER 6:
JOBS, TRAINING AND
VOCATIONAL ASSESSMENT**

CHAPTER 6: JOBS, TRAINING AND VOCATIONAL ASSESSMENT

The State Council on Developmental Disabilities says that the unemployment rate for people with some type of developmental disability is 80 percent. If that statistic is based on the same definition of unemployment used by the Bureau of Labor Statistics, it means that for every developmentally disabled person that has a job, there are four actively and unsuccessfully looking for a job.

The State Council and the Governor's Committee for the Employment of the Handicapped have been working very closely with the State Job Training Coordinating Council to make sure that federal funds coming into the state under the Job Training and Partnership Act are appropriately and fairly shared with disabled people in need of training and employment opportunities. A very important resolution was adopted by the State Council and the Governor's Committee on this and related issues last fall, and is included in the appendix. The resolution calls for many types of positive action by the various organizations funded under the Job Training and Partnership Act, and specifically calls for representation of the disabled, on advisory groups to these organizations.

People First is fully supportive of the resolution. It recommends that in any further efforts along these lines, the State Council and the Governor's Committee adopt the position that any representation of the handicapped population on the State Job Training Coordinating Council should always be done by a person with a disability and not by an employee of an agency that serves the disabled. Furthermore, it should be recom-

-ended that Private Industry Councils at the local level (PICs) make every effort to recruit disabled businessmen to serve on their boards and committees.

People first feels that the efforts of the State Council and the Governor's Committee on Employment of the Handicapped are well-directed and energetically pursued. They represent input "at the top". It is hoped that those efforts can be helped to have a greater impact by what this report contributes in the form of "input from the bottom".

Resident at a Group Home: . . . If you're living here you got to follow the rules and go to a workshop or some other daytime program until you get a job. That's one of the main rules

Task Force: Many People First members in Sacramento have left the workshops and adult education center because they felt they were being made more retarded by being there than if they didn't go there. The discrepancy between living in their very own apartment and being responsible for their lives in that area and then going to a workshop and being treated like a young child was making them crazy, and they found it easier to try to get their lives together without the benefit of a workshop.

However much the task force may have become an almost organic unit for purposes of putting together this report, it is still just a bunch of very free, very opinionated and assertive - and some people say argumentative- individuals, who often have to fight very hard with each other *before they reach an agreement on an important issue.*

There is one matter, however, on which there is no argument whatsoever. No member of the task force ever wants to see another ceramic windchime.

These have become the hated symbol of the alleged vocational training system of sheltered workshops - which neither train nor offer a vocation, except to the people who run them.

Enough has been stated elsewhere about the monumental unsuitability of the sheltered workshop system that this report needn't beat a dead horse. No report on the developmental disabilities service system would be complete, however, without examining in general the entire system's unique inability to assist its clients toward economic self-sufficiency.

Several members of the task force know a disabled man whom the vocational rehabilitation system kept trying to teach how to make brooms. That man, with help from people outside the system who recognized his exceptional potential, eventually became a high official of the federal government with a great deal of influence over the nationwide vocational rehabilitation system. Even from that position, however, he was able to make almost no dent in the business-as-usual mentality of the system. The irony is, that over the years it has so successfully resisted efforts to bring it up to date, the vocational rehabilitation system has become increasingly irrelevant to disabled people who need vocational services. It may survive in some other context, but until it re-evaluates its perceived charge towards people who want to work, its main importance is as a bureaucracy that spends money that could be better used some other

Task Force; How many things do you learn at your vocational training facility besides making windchimes or learning how to scrub pots and pans? . . . Suppose a group of you decided you wanted an expansion of training opportunities — would they listen to you?

Trainee; That would be fun. I think they might, in a way, if you really sit down and talk with them and say "Hey, lookit, how about trying to expand the program a little bit . . . why don't we get to learn to do more things? . . . We'd really like to have a choice."

Task Force; We've noticed that this fellow here is a very skillful bike rider. Why can't he be taught to repair bikes? . . . You can make a good living at that . . . You folks should know about a program in Sacramento that has gotten money (from the Job Training Partnership Act) to set up an on-the-job training program for people with developmental disabilities . . . What's so incredible about the program is first they ask you what you want to do, then they go out and try to find you a training slot in the community that is in the field you want . . . or if you find a place with a training opportunity by yourself they'll help with the training costs. Can you believe that?

Trainee; Well, in our workshop they ask us what we want to do. Only thing is what we get to do is make windchimes or wash dishes.

* * * * *

Task Force: So you're advising people with mental retardation not to go to places like workshops or segregated adult schools, and so forth. On the other hand, you told a story a few minutes ago about what a good thing it was to go to a school like that and be able to be in a certain teacher's class

Consumer: No, it wasn't at that school. It was the same teacher but at another program. It was just when the program was getting started, and at that time it was a lot different . . . It wasn't oppressive there . . . That's the time when they asked us what we wanted to learn. That was the first time we would be at a place where they would hear us what was going on. That was the first time people would hear us . . . It was at that minute that I first time really wanted to learn to read

At one point in the task force's discussions of vocational issues, somebody talked about what an "idiot savant" is -- that is, a mentally retarded person who may have a special talent of great significance or value to society. The discussion, livened by that almost joking comment,

turned seriously to people's observations of how little genuine effort is put into digging for hidden talents or skills when a "vocational assessment" is done of a person with developmental disabilities. A newcomer to the scene, for example, noted in passing that one of the members of the task force has an exceptionally fine speaking voice. That is a talent which, with the right kind of follow-up and training, could conceivably lead to a job in radio or television, or in making talking books, or in any number of activities. The point is that this man has an obvious talent which has never been examined by any of the service providers who have given him vocational guidance, counseling or training - so that he has never even considered it a potential marketable skill, let alone had an assessment of that potential, or advice on how to do something about it.

This bears on the issue of the Individual Program Plan (IPP) required by the Lanterman Act for every client of the developmental disabilities service system. The comments and complaints were heard everywhere the task force went that the IPP is too often treated as just another bunch of papers to fill out. There was a strong feeling that this "ho-hum" treatment of the IPP where it happens, reflects the attitude that people with mental retardation have so little growth potential it almost isn't worth bothering. Some consumers, who said they had respect for their regional center workers, felt that there was a "burn out" element working when a perfunctory IPP was done, because these workers were so frustrated at trying to find good service resources for their clients. As the Assembly Office of Research report confirmed:

"We found that the individual planning process can be a mere ritual, however, when available services are limited in variety or quality, and when the program coordinator's time and energy are spread over too many clients. Under such conditions, an available service is commonly rationalized as being what the client "needs". For example, a person's need to work and earn money can be rationalized as a "need" for a sheltered workshop, when, in fact, the workshop might be only one of several ways to obtain job training. By confusing client needs with available services, the individual program planning process can perpetuate a limited range of available services." (Pp. 30-31.)

The widespread presence of these two critical barriers, lack of belief in a client's vocational potential, and off-handed, line-of-least-resistance referral to existing services, however inadequate or inappropriate they may be, must be overcome before the system can more generally reflect adherence to the intent of the law.

Surely there must be well-documented tests and other methods of assessing vocational potential that can do a better job of looking for hidden vocational potential in people with mental retardation. Certainly the language of the Lanterman Act does everything possible to avert pro-forma referral of clients to segregated, retarding services:

. . . Initial intake (of a person with developmental disabilities by the regional center) shall include, but need not be limited to, information and advice about the nature and availability of services provided by the regional center and by other agencies in the community, including . . . education, work activity and vocational training . . . and other services or programs that may be useful to persons with developmental disabilities . . . Intake shall include a decision to provide assessment. (Welfare and Institutions Code Section 4642)

. . . Assessment may include collection and review of available historical diagnostic data, provision or procurement of necessary tests and evaluations, and summarization of developmental levels and service needs . . . (Welfare and Institutions Code Section 4643.)

Individual program plans . . . shall include the following: (a) An assessment of the developmentally disabled individual's capabilities and problems. The regional centers, in cooperation with the (Department of Developmental Services), shall adopt an approved list of tests to be used by all regional centers in making such assessments. The test or tests shall have been determined to be reliable and valid by acceptable statistical methods . . . (b) A statement of specific . . . objectives for improving the capabilities . . . of the person. Such objectives shall be stated in measurable terms which allow measurement of progress . . . (Welfare and Institutions Code Section 4646.)

. . . No purchase of service contract with any agency or individual shall be continued unless the regional center and the person with developmental disabilities . . . agree that reasonable progress has been made towards the objectives for which the service provider is responsible . . . (Welfare and Institutions Code Section 4648.)

Even if it is not possible in the near term to move the system to provide in-depth assessment of the vocational potential of every client, it is possible to illustrate what needs to be done, and what can be done for so many clients of the system – because it is being done already in at least one place – in a cheaper and more normalizing way than the traditional vocational rehabilitation model has been able to demonstrate.

The following is a conversation between the task force and the manager of a "make-your-own-sandwich" shop, which was established by a private group that supports the creation of quality services for people with developmental disabilities.

Manager; . . . (She) left us for a new job yesterday . . . Right now I'm missing her terribly, not personally but because the store has grown to depend on her. We don't pretend people are important here - we have real work . . . One guy that's in here now has moved on to a job with a fast-food chain, and I called him over to meet with you as a kind of example of somebody who's moved on to regular employment. He's also somebody I call on for help when I'm short-staffed. Just that sentence tells you that we don't have pretend work. I don't call Jeff because I have pretend work. I call him because I've got real work that I can't get done.

Task Force; When you call him back, does he get at least minimum wage? (trainees don't)

Manager; Oh, yes. He's moved on and he qualifies for payment just like any other regular worker.

Task Force; On the cashiering, how do you handle that?

Manager; That's tough — depends on the individual. We are willing to give anybody a shot at any job — we don't necessarily demand that everybody learn every job absolutely perfectly, but we do demand that everybody be given a chance to learn without any preconceived notions of what their limitations are . . . we won't put anybody in a situation that's set up for failure, but we're willing to give anybody a shot.

Task Force; Wouldn't you say that chances of placing anybody as a cashier from here is going to be minimal?

Manager; And I've learned that lesson. I did try a woman who was good at all aspects of the work in this place on the cash register and she did marginally well. She went elsewhere for a job and they said "Do you do cash register?" and she said yes and they tried her out but she was not employed at that job . . . The fault, if there is any, is mine in that there was a false sense of what she could do when as a matter of fact in the real world she just couldn't do that job. She did get employed at that same organization at other tasks and in fact she's doing wonderfully . . . but the cash register was something she wasn't competitively employable at.

Task Force; How do you teach a person with learning disabilities to do all these tasks?

Manager; It's doing it, it's showing people how to do it -- it's tactile learning. One of the mistakes we've made . . . is that they've had classroom training, they've had vocational classes . . . Vocational classes, to folks who have learning disabilities, don't make any sense . . . You have to feel it, to experience it . . . doing it seems to be the best, the only way. Show them — two, three times; have them do it with somebody else; then have them do it alone. It's a step-by-step process, like learning to ride a bicycle.

Task Force; How long does it take?

Manager; As long as it takes somebody to get ready.

Task Force; So then it doesn't matter how long it takes?

Manager; It doesn't matter how long it takes . . . and this is the toughest decision I have to make . . . it's whether somebody is going to be able in the long run to make it in competitive employment . . . That's the key thing — they're not going to make it here if they're not going to make it in a regular job. We have to create a real job situation here so if they're going to fail they're going to fail here.

You know, I was talking to somebody yesterday about success rates. Well, if we had a tremendous success rate that isn't anything to brag about Success stats are often created by taking only people who are going to be successful, and not risking. We hope to risk, we hope to fail — I wear my failures as a badge of success of the store

Task Force; How do people get in?

Manager; All different methods — Department of Rehab, school system, city college, independent living programs, parents, coverage on radio and television We work with about seven or eight different people in a week We have a waiting list that works depending on the needs of the store. For example, if X lose John, who's real high functioning, to a job in the real world . . . and there's two people who have applied, Sally — who has a lot of work background — and Jim -- who hasn't had a lot of experience with work. If John leaves, Sally's going to take his place because I need that chemistry, that balance. But if somebody who was not as advanced as John leaves, Jim will take the place, because the one who wasn't the greatest worker in the world can be replaced by somebody we can take a bigger chance on . . . I make that decision.

Task Force; Rave you had experience with somebody who doesn't move very fast?

Manager; Just recently we had somebody here straight out of high school. He lacked what you folks have gained through years of being out there fighting the system — he lacked experience and maturity. I found that I had some trouble working with him because he just needed some more years. I found him socially immature . . . and that's one thing that's a characteristic of our store - you might call it a limitation - but we have to make our money from our customers. This is not a subsidized operation. So consistent inappropriate behavior with customers is something we can't tolerate, or we lose the business that keeps us operating.

Task Force; So how fast do you terminate somebody who's not right for you?

Manager; Probably not fast enough. He kept that fellow about six weeks, and I knew the first week he wasn't going to make it . . . He had the potential of learning the skills, but it was behavior . . . So we worked with him and got him into another working situation, a bank job that didn't make him have to work with customers to give him a chance to learn under less pressure . . . This is tough here, this is tough. Customers are in and out and they're demanding and they don't know anybody's "special" so they don't treat 'em special. Isn't it nice not to be treated "special"?

Task Force; (Laughter, cheers and applause.)

Manager; You know, I was dealing with a father and he says "We have four children, but Sally here has some learning difficulties — but she's our special girl. We don't make her do anything around the house." Now who wants to be that special girl?

Task Force; It's really a neat thing to see what you're doing . . . we need more people to do that kind of thing . . . Jeff said, when we were talking about his experiences here, that you ended up being a friend he could really talk to — there was a relationship and an attitude where he could turn to you where he couldn't turn to counselors and others.

Manager; That's interesting, because if there's one thing I am, it's the boss. And if you talk to Jeff's replacement, who hasn't been here very long, he won't tell you I'm a friend. To him, I'm THE BOSS. He's talking to somebody and I walk in, he gets back to work. He's afraid. And that's the way I want it to be. But what will happen is, gradually, as that person begins to develop abilities and they get to be really good at what they're doing, they begin to develop self-confidence . . . I'm not friends with people we're training, I don't want to be their daddy, their mother-in-law . . . but they gain self-confidence, then they gain self respect, then they gain my respect and the respect of the other workers. Then the relationship begins to change and become a much more personal thing. We don't start off that way because most of our people are so used to counselors, to social workers, and so used to special ed teachers, and so used to doctors and all those people who make them feel like they're "taken care of — so at first there's a strained relationship between us, and I don't want to be anything but the boss, because probably their parents or their social worker told them "Oh, you're going to this program, and the man who runs it is a very nice man." I try to change that opinion real quick. Eventually, what happens is that a real relationship grows, but it grows not between daddy and the kid or between the social worker and the client, but between co-workers who have gone through the wars together and have a respect for each other. That's a real relationship.

CHAPTER 7: FINANCING INDEPENDENCE

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FINANCING INDEPENDENCE

A large number of persons with developmental disabilities are eligible for a federal/state income maintenance program called Supplemental Security Income (SSI). This program is the descendant of the old welfare program of Aid to the Disabled. It uses a means test (how much money and other assets easily convertible to money do you have, and how much income do you get each month from whatever source). If you are eligible, you can receive money to live on from the government. The amount is less than \$500. The rules are extremely complicated, and this is not the place to go into detail about them.

If you are eligible for SSI, you are generally eligible for a publicly funded program of health care called Medicaid in other states, Medi-Cal in California.

If at any time an SSI recipient accumulates more than \$1500 in money or resources easily converted into money, that person will usually become ineligible for SSI and Medi-Cal. If a person's income exceeds a certain amount, the same thing happens, although the tax on income is not 100 percent, as it is on savings that add up to more than \$1500. In any event, the tax rate on income or savings of SSI recipients is generally higher than on millionaires.

It is extremely difficult to get back on SSI when you've been cut off. For developmentally disabled people living in residential facilities, SSI

is the most usual source of money to pay for the room and board of the residents, so the residence doesn't want people cut off. Usually, the SSI check of people who live in residential care facilities goes directly from the government to the facility, so the loss of eligibility creates an immediate cash flow problem for the facility.

People with developmental disabilities can be eligible for Social Security under a variety of circumstances, which are also too complex to go into in this report. Different rules apply to income under Social Security, and liquid asset limits don't apply. But because many Social Security recipients depend on Medi-Cal instead of Medicare (the Social Security health program), exceeding the income and resource limits of Medi-Cal can get a person into trouble.

If you expect to be dependent on SSI or Social Security for the rest of your life, you simply have to be careful that you don't break any of the rules, or that there's a little bit of money around to hold you over if you do make a mistake - or if the system makes a mistake and you have to pay for it.

On the other hand, if you're trying to work your way out of dependency, but are dependent on SSI and/or Medi-Cal until you can get a decent paying job that looks like it might last, you can run into unbelievable problems trying to figure out how to make ends meet during the transition. There are some very hard-to-understand rules that an occasional recipient

with a smart lawyer figures out how to use to put aside extra money for future needs, but the situations in which these rules apply are very limited.

The following dialogue between a resident of a care facility and members of the task, force sums up a great deal of the income-maintenance headaches of people with developmental disabilities, and opens the window on a novel idea.

Resident: . . . I've got almost the \$1500 . . . so the administrator says "O.K., you gotta go out and spend." So I go and spend for all this foolish stuff I really don't need.

Task Force: . . . Maybe what is needed is a good investment service for people on SSI so that they can acquire things that will increase in value.

Resident: No, we can't have any . . . investments.

Task Force: Sure, you can have a piece of antique furniture or an oriental rug.

Resident: No, once a year they come with these papers . . . and they ask these personal questions (about assets) . . . so us kids here have to go buy foolish things they don't need in order not to be cut off . . . One boy, his parents bought him a burial plot and they cut him off because of that

When we get a job, we gotta know how much we gonna make . . . if you make too much they cut you off and then if you lose the job you gotta fight to get back on . . . They want you to work and if you do they cut you off everything and you're worse off because of Medi-Cal . . . so that's why a lot of people who could work don't and I could see their point unless they get a job that pays decent.

Task Force: . . . Maybe an IRA (Individual Retirement Account) might not be a bad idea . . . A tax sheltered investment . . . Businessmen do that, don't they? They make up to a certain amount and they know the tax man is going to take it away, so they invest it (in a sheltered account).

The IRA suggestion by a disabled task force member became the subject of serious discussion when the task force began working on recommendations. By then, the task force had heard variations on the same theme of how the SSI system keeps you poor, keeps you from working your way up in a job, keeps you dependent because it doesn't let you ever break out of the cycle — and realized what is meant when people say "If you're developmentally disabled, and especially if you're labelled mentally retarded, there's one thing you can count on -- you're going to be poor and stay poor -- the government will see to that."

What is being called a "tax" on earnings and savings under SSI must, in all fairness, be recognized as an effort by government to reduce the cost of the program to taxpayers, since SSI is financed out of general revenues. Even when society acknowledges that it has an obligation to transfer money from people who have enough to help take care of people who don't have enough, and makes that transfer through the tax system, government, which manages that transfer, also has an obligation to try to keep costs down for the sake of the people who are having the money taxed from them.

The problem is that when a program like SSI is so badly put together that it keeps people dependent on it who could make it on their own with the right kind of encouragement, and when the program encourages recipients to go out and waste money to stay eligible, the taxpayers certainly aren't getting their money's worth.

Ending dependency wherever possible should be the goal of all programs for disabled people. If you look at how the disincentives in SSI work, you see that disincentives to earn and save make no more sense to poor people than they do to better-off people. The idea of the Individual Retirement Account (IRA) grew out of the understanding that tax reform could create some important social benefits. First, by allowing a portion of earned income to be put in savings that couldn't be touched for a long time, the amount of capital available for investment in building up the national economy could be increased. Second, by not taxing that income at the time it was earned, but rather at the time it is taken out of the IRA, it encourages people to work harder now and earn more money if they can under the preferred tax rates, and this also benefits the economy by improving productivity. Finally, as more people set up larger "nest-eggs" for their retirement, the future pressure on Social Security and other pension programs will be reduced.

Why can't these same general principles be applied in SSI and related programs with people with developmental disabilities who have a clear potential for improved independence and eventual self-support, or at least significantly enhanced earning power? The government could forego some of the cost-reducing take-backs in the short run, just as it foregoes present tax revenues in the IRA program, in return for long-term benefits and ultimate reductions in overall costs.

Suppose the adaptation of the concept were called the IIA - Individual Independence Account. A person who signed up for the plan would have

to promise not to have control over the money, but have it kept in a kind of "trust" subject to certain conditions - just as an IRA is. If the person broke the agreement, he or she would be subject to penalties that would be clear when the agreement was made - as in IRAs. Then, if the person earned money or saved money above the limits allowed under SSI, that extra money could be set aside in an interest-bearing IIA. Probably a limit on how much extra money could be sheltered that way in any year would be appropriate, just as it is in the IRA system.

The agreement to participate in the IIA program would state the conditions under which the money could be withdrawn. It would help consumers and service providers develop much more specific goal orientation in their Individual Program Plans, which probably should be the basis for deciding how and when the IIA money can be withdrawn. The costs of acquiring and furnishing an independent living arrangement might qualify. A special vocational training program that isn't available under public funding might be a proper reason for making a withdrawal. So might buying a car or other means of private transportation if it's part of a plan for independence and self-support. Perhaps the money might be made available to finance the cost of health insurance during a transition period from public dependency to economic independence.

One of the possibilities of considerable interest to the task force was permitting the sheltering of excess income and resources to enable an individual or group of individuals to generate capital for a business enterprise. For example, People First members have discussed the possi-

bility that they might make very good proprietors of a residential facility for disabled people. Not only do they have a keen desire to see such facilities run properly, but they also have, individually and collectively, an enormous amount of insight into how things can be done wrong, which is an important step in avoiding mistakes.

The possibility of an IIA being the source of seed money or earnest money could be just what it takes to generate additional investment capital in such an enterprise.

Given some genuine commitment to innovation, and the willingness to take a minor risk, and given the exercise of the opposite kind of imagination that now goes into making SSI an absurd and costly "Catch-22" for people with potential for independence, the possibilities are exciting. The task force recommends that the State Council on Developmental Disabilities take a serious look at this idea, and bring it to the attention of its counterpart councils in all other states. That way a national constituency with respect and clout can bring the matter before the Congress of the United States, which would have the power to adopt such a plan.

There is a program administered by SSI called "Plan for Achieving Self-Support" or "PASS", which is available to the blind and disabled receiving SSI under very tightly controlled circumstances. This program is very complicated and full of bureaucratic control. However, it might be a good starting point for working out the more flexible parallel to the IRA

suggested here. It might be useful for the State Council on Developmental Disabilities to find out how many people receiving services to the developmentally disabled are using the program, or even aware of it, and find out what those who are using it think about it, and how it is working out. In any event, the task force has obtained SSI regulations and administrative guidelines for "PASS" and is including them in the appendix for use by consumers and their families pending the hoped-for development of the IIA plan.

**CHAPTER 8:
SUCCESS STORIES**

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Several places in this report one of the members of the task force has been used as an example of how much retardation seems to be the product of the retarding environment.

This young man, now in his early twenties, has been diagnosed from a strictly medical point of view, with reference to the measurable biological damage that has occurred in his brain and the effect that damage has on his intellectual functions and on the rest of his body, as "severely" retarded. (For people who take serious stock in the concept of "IQ", the upper level of severely retarded has been established at around 50.)

And yet he is the most normal -- and "normalized" -- of the members of the task force who have been diagnosed as having developmental disabilities.

He drives a car. The law explicitly states that:

. . . persons with developmental disabilities have the same rights and responsibilities guaranteed all other individuals by the Federal Constitution and laws and the Constitution and laws of the State of California. No otherwise qualified person by reason of having a developmental disability shall be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity, which receives public funds. (Section 4502, California Welfare and Institutions Code.)

He found a teacher to take whatever extra effort it might require to teach him to drive. He took the California driver's test - written and road - which is publicly funded, and passed.

He can pick up the phone and call any friend he wants to, disabled or non-disabled, and ask: "What are you doing tonight? Want to go to the movies? Good. I'll pick you up at seven."

He couldn't leave Sacramento with the rest of the task force because of his job. And so he had to get himself out to the Sacramento Airport, catch a plane for Los Angeles International, make his way from one airline to another in Los Angeles International, catch a plane for Santa Barbara and meet his colleagues there. In the course of this adventure, which had been known to reduce many a "normal" traveler to whimpering, he ran into a high official in the field of special education, whom he happened to know. "Blew his mind" was the observation - and accurate because what that official's service provides neither expects or aims at revealing those capabilities for normal living.

In Chapter 10, a young man identified as Paul is described. At age 18 he couldn't roll over by himself; he could be sat up in a chair but he couldn't get to his feet. About all he did was rock, either lying down or sitting. At age 22 he can walk, he can feed himself, he can brush his own teeth. He attends classes at a school. He is learning to dress himself. His mother, who has either taught him all this or has supervised the teaching, only began to believe what was possible five or six years ago. Now she is a beacon of hope to other mothers and fathers through the program she has put together, as Paul is a symbol of hope.

There are probably hundreds, or thousands of stories like this in California — or potential stories, if the system can be made to do what is known to be right and effective. Surely, therefore, there must be a couple of dozen real success stories that can be compiled for review by primary and secondary consumers, by service providers, by politicians, and by the media and the general public to help people realize what is possible when you do things right. This would be no different from the effect the story of Helen Keller had: "Isn't it incredible what is possible for human beings to achieve?"

A collection of living success stories, if honestly and sensitively done, could also embody by example the principles and techniques of how to do things right. The most unsatisfying and uncomfortable thing about preparing this report is the realization of how much easier it is to tell what's wrong than to say how to do what's right. On the other hand, one of the most rewarding things about doing this report is finding out that some people are doing things right, and that there are good results to show for it. A study of the life experiences of people who have achieved normalization is one of the ways to learn how to achieve normalization.

To other consumers, the task force seemed to be an "anthology" of success stories. Members of the task force are honest enough with themselves to know that in many ways that's more appearance than reality. But there is no question that one of the unanticipated impacts of doing the work of the contract was stirring up a sense of their own potential among the people who were interviewed.

It is recommended that the State Council on Developmental Disabilities adopt as a major, ongoing responsibility the collection and analysis of biographies of people who have been especially successful in achieving normalization, deinstitutionalization, reevaluation, and all the other "-ations" the developmental disabilities system identifies as principal goals.

These biographies should be prepared in whatever variety of modes and media necessary to make them accessible to as many consumers as possible, and of course to the community at large. The effort might be kept constant and current by publication of a yearbook in the manner of encyclopedias.

From the standpoint of system improvement and reform, the process of gathering biographical data could eventually become an important tool for research and analysis, especially in comparing what services are most effective with what services aren't.

The California Council might consider making this suggested project a joint effort with developmental disabilities councils in other states.

**CHAPTER 9:
HELPING FAMILIES DEAL WITH
DEVELOPMENTAL DISABILITIES**

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In Chapter 4 one of the points made about the "generation gap" is that a large portion of the unmet service needs of the present day comes out of a need to undo the effects of bad or misguided services in the past. It is an ironic fact that a large number, perhaps a majority, of people who are labelled mentally retarded and who are functioning quite normally in the community are people who were lucky enough not to have fallen into the "wet concrete" of the retarding environment of traditional services. In many, many cases, the success stories of these people revolve around the success of the people who love them - usually their parents - in getting them the right services when they needed them and at the same time preventing institutionalization, in the broad sense, by the organized service system.

Secondary Consumer: If you only knew how much counseling for families is based on helping them accept retardation and all the limitations that go with it instead of helping parents learn how to work at overcoming retardation . . . What I'll never understand is what keeps some of these so-called helpers from believing what they see!

For parents of a child born with a developmental disability or suddenly acquiring a disability in childhood, nothing could be more important than the immediate discovery of a support network of people who do understand, and know how to help find the right kind of services. Parents going through the shock of finding out that they haven't got the "million dollar baby" need to be helped to deal with the truth as quickly as

possible – and that truth includes knowing the worst that can be expected and also the best that can be expected, given the state of the art. They need to see examples right away of the best, and they need to be helped to understand that successful overcoming of handicaps which would have seemed impossible just a few years ago are becoming commonplace today. They need to learn right away that the technology of treatment is advancing rapidly – unfortunately more rapidly than the comprehension of the keepers of the old way of doing things.

People in and out of the system who want to see reform and progress in deinstitutionalization and normalization must focus on helping families cope as a top priority. Not only will getting this service widespread and effective prevent the need for many other more costly and less effective services, but it will also recruit a new generation of secondary consumers to hoping and to helping.

Primary Consumer; . . . When my mother found out that I was disabled she didn't want to believe it . . . but one of my relatives told her because I wasn't able to sit up in the normal way after six months . . . My mother had a hard time accepting me as a disabled person and she would try to treat me as if I wasn't . . . but she really didn't know how . . . She would try to get me to do things that I really couldn't.

I reached a certain age and had a hard time accepting myself, and when you have a hard time accepting yourself because you're disabled it's a real battle for you . . . When I saw my brothers walking around, when I saw my brothers going out and playing and being able to do certain things I was heartbroken within myself because I wanted to be like them, and X couldn't be like them.

. . . So I had a difficult time and so did my family. But what brought me out of my shell was when I left home and found out some people really did care . . . I guess my mother felt she really did care but I guess she was the type of person that really couldn't show how much she cared . . . So I more or less based myself on being around people than around my family.

Primary Consumer; . . . When things would go wrong I would be getting punished because X was there all the time . . . In other words when my mother had problems I felt like she was taking those problems out on me . . . So when I was a teenager I left home and went to a state hospital . . . (Finally) I went to a private home . . . but they put somebody in there who was emotionally disturbed who started scaring me, so they put me in a convalescent home for three years and then another convalescent home for three years and then another one . . . and then for a while I was with a private family who worked in the convalescent home but they put me back because things didn't work out . . . and like I said, I've been in so many places that it's hard to remember.

This person's experience hardly fulfills the letter, much less the spirit of the Lanterman Act that:

services should be available to enable persons with developmental disabilities to approximate the patterns of everyday living available to nondisabled people of the same age . . . (and to) the maximum extent feasible, services should be available throughout the state to prevent the dislocation of persons with developmental disabilities from their home communities. (Welfare and Institutions Code Section 4501.)

The primary fault, however, lies with the absence of services to that person's family right at the beginning when somebody noticed something was wrong. When that person was a baby, the Lanterman Act didn't exist, and the ideas that were behind it hadn't had much attention paid to them in this country. And so the long nightmare of being kicked around from facility to facility may have been inevitable. That is no longer permissible:

The Legislature places a high priority on providing opportunities for children with developmental disabilities to live with their families, when living at home is the preferred objective in the child's individual program. In order to provide opportunities for children to live with their families, the following procedures shall be adopted:

(a) The state plan shall give a very high priority to the development and expansion of programs designed to assist families in caring for their children at home. Such assistance may include, but is not limited to: specialized medical and dental care, special training for parents, infant stimulation programs, respite for parents, home-maker services, camping, day care, short-term out-of-home care, babysitting, counseling, mental health services, behavior modification programs, special equipment such as wheelchairs, hospital beds, and other necessary appliances, and advocacy to assist persons in securing income maintenance and other benefits to which they are entitled.

(b) In developing individual program plans for children, regional centers shall consider every possible way to assist families in maintaining their children at home, when living at home will be in the best interests of the child, before considering out-of-home placement alternatives.

The department (of developmental services) shall conduct an annual review of the percentage of children in out-of-home placement, relative to caseload, in each regional center, and shall investigate any possible excessive out-of-home placement in any regional center. If the department determines that a regional center has failed to emphasize assistance to families to care for their children at home, the department shall assist the regional center to develop a more appropriate program and shall establish specific home-care objectives for the regional center to meet in its contract with the state.

(c) If the parent of any child receiving service from a regional center believes that the regional center is not offering adequate assistance to enable the family to keep the child at home, such parent may initiate request for fair hearing

(d) Nothing in this section shall be construed to encourage the continued residency of adult children in the home of their parents when such continued residency is not in the best interests of the person. (Welfare and Institutions Code Section 4685.)

The task force has included this long quote from the Lanterman Act because it knows of outstanding home-care assistance programs whose funding is both inadequate in amount and shaky in continuation prospects. Considering the ability and willingness of the Legislature and Governor to agree on more than two billion dollars in additional funding for education

over recent years, there ought to be a way to find three of four million dollars to secure and expand the best type of education possible - teaching parents how to keep their disabled children out of the retarding environment and out of \$5000 a month state hospital beds.

People First thinks the Legislature should schedule hearings on this important subject at key locations around the state so that parents, care providers, and interested parties can make their views known. The Legislature also ought to commission a study of this special subject, perhaps by the Assembly Office of Research, which has done such a good job on its other assignments in this area.

One of the saddest things the task force encountered over and over again, something which some of its own members have to live with, is the difficulty of getting families back into positive relationships with one another when a disabled member has managed to get his or her life in order after leaving home. We are not aware of specific services focused on this matter. There may be such services - if they exist, they should be publicized by the appropriate agencies. If they do not exist, it is something for the service planning agencies to take under consideration.

Another matter in strengthening families to work with disabled members is in the area of preparing for the eventuality that the parents will no longer be able to assist their children to live at home because of

the parents' own infirmities or death. This means that even when disabled people are functioning well with their parents at home, developmental disability system services should be made available to maximize the independent living potential of those disabled individuals. The task force ran into many state hospital and other residential care facility clients who only became institutional "cases" after their parents died:

. . . After my mother died I took care of my daddy . . . I took care of the house and I fixed meals . . . and then my daddy has a heart attack and — I don't want to talk about it. . . . Then my brother sent me here . . . I like it here because there's things to do, but I don't like living with so many people . . . I like my roommate very much, but I'd rather live with just a few people with a roan to myself.

**CHAPTER 10:
SUMMARY OF UNMET
SERVICE NEEDS ISSUES**

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The task force visited a program that has been in existence about four years. It was begun by the mother of two developmentally disabled children. Paul is now 22 years old, and by technical definition profoundly retarded. Rachel is 23, and severely retarded. The mother, Susan, had refused to institutionalize either child over the years. However, it was not until recent years that a powerful conviction began to suffuse and motivate her — namely that the growth potential of her children was enormously greater than she had been led to believe in earlier years.

The lengthy excerpts of the interview with this woman, who is both a secondary consumer and a service provider, turned out to be the best summary of most of the really critical issues in service that the task force could imagine, far more moving and insight-provoking than anything somebody might just sit down and make up.

Susan; When I started this program with Paul four years ago he just mostly sat and rocked . . . his hands were flipping back and forth . . . he didn't play with toys . . . he had never slept through one night in eighteen years . . . He didn't feed himself . . . He could sit in a chair but he couldn't come to a standing position from a chair.

. . . I had some girls come in to work with him under my supervision on a daily basis . . . and he showed such remarkable improvement after just one week in this home program that X decided to make a film of it. X took it around the state . . . and met some wonderful people who were interested in supporting the idea of an in-home training program . . . we've been going ever since.

. . . In the first year of the program he wasn't able to get up from the floor — he couldn't get up on his knees. He didn't learn that the second year or even the third year. It was the fourth year - last year - that he finally did that. But the first year he learned to feed himself . . . and a little playing with toys . . . He still hasn't learned to dress himself but I know he will . . . in the fifth or sixth year.

. . . The skills that he is learning now are going to last him the rest of his life. They are going to make the difference between his going into an institution or having someone be able to merely assist him in self-help types of skills in a semi-independent setting.

I just believe 'home-grown' kids are the best kinds of kids. I think we really need to take a look at the way we're raising children these days, and what child-rearing is all about . . .

Task Force; Yes, but what about when these people get to be adults, and it means someone has to go on being a ~~momma~~ for many, many years, long after most mothers have stopped playing ~~momma~~?

Susan; Well, it's a matter of delegating some of the responsibilities . . . I get people in to help, I monitor them, I guide, supervise . . . I'm not the hands-on person that does everything myself for the children as if they're three or four years old . . . The point is getting them to do more things for themselves, by connecting them with the kind of people who can teach them what they need to know to be able to live their lives to the fullest . . .

Task Force; We know there are children who simply can't remain with their biological parents. Do you think you can transfer this intense kind of caring and parenting to a situation where it isn't the parents that take care of them?

Susan; Home environment doesn't have to be the natural home environment. After all, there are home environments that aren't nurturing and caring — all too many in this society. In a community setting, where you have people interacting with people, where you have the normal flow of events — that can be what is meant by a home environment as opposed to an institutional setting where you don't have that natural interflow with your next door neighbor or the guy at the grocery store. For example, there is a residence in Los Angeles where three or four children live with houseparents who aren't their biological parents, but it's home . . . I don't know how I can describe how it's different from traditional small group homes . . . but it's a gigantic step over convalescent homes and the state institutions. It's terrible that we are still placing people in institutions.

Task Force; Won't you try some more to explain what makes the good places you mentioned unique as far as the developmental disabilities system goes?

Susan: Hell, I think it's the emphasis on the individual person that's present . . . • they don't go to the store and purchase six identical sweaters and put them on the people who live there. Each person goes to the store and helps pick out his own sweater.

Task Force: Do you think it makes a difference in that Los Angeles place that the natural parents have to live nearby?

Susan: Yes, they have to attend regular meetings there, and maintain contact with their children . . . But also, when we have a parent-monitored program the care providers tend to show a lot more concern about how they're running the home.

Task Force: Back to the question of what is a home environment. The service system and the lawmakers don't ever seem to have been able to get a handle on criteria that really identify it, and yet you have to acknowledge that it has a real meaning . . .

Susan: I was asked that question today by the regional center because X was looking into a possible respite care center for Rachel and they asked me what it is I would look for. And X told them to go out and evaluate these places and came back with their highest recommendations to me. They didn't want to do that.

Off the top of my head -- for my two individuals -- the kind of place that X think would be both nurturing and educational, that would be supportive to them as growing individuals, would be in an atmosphere based on approaching them where they are. With Rachel that would mean talking to her, asking her what she wants, what she thinks, what she feels, rather than telling her what to do . . . helping her to develop whatever skills she needs to be as independently functioning as possible . . . One would need to talk to the people in charge and find out what their philosophy is concerning how people grow, and what kinds of experiences an individual needs to have in order to unfold their potential.

I know that Rachel has communication problems. She needs help in that area. I know she's mixed up about some things, and that she's lonely — it's important that she can tell me about that, and then we can get what help we need. It would be the same thing in a foster home that is a home -- someone would need to listen to her and be sensitive to what she feels is important and that will help her live her life to the fullest . . . • . The person in charge of that program should know very well what services are available to a disabled person . . . But what do you do when you call up thirty agencies and there's no psychiatric help available (for a young woman with communication difficulties) . . . which is what happened to me.

The person that runs that home better be able to pull some rabbits out of the hat, stick with it until the system gives you the answer you want . . .

So it's going to take an assertive person, one who would advocate for the rights of somebody who isn't yet able to advocate for herself or himself . . . • Paul doesn't have speech, so he couldn't speak for himself. But someone could get to know him on his level and say: "This is where he is. These are his strengths upon which skills could be built." He can't tell you that he could do these things, but there are ways to find out, and then he can be helped to learn to do them . . .

Task Force: I know these are things people don't like to think about, but do you ever think about what might happen to your children if something happened to you — if you died or got sick and couldn't take care of them?

Susan; That's a real good question . . . What Rachel and I are working on is for her to learn to be able to do as many things as she can for herself, and then if something were to happen to me — and I've made a will to this effect — then Rachel would be able to choose a place where she would like to go and live — perhaps a group home, if that's what she would like to do. She talks sometimes about finding a nice young man to share her life with. So there's some possibilities there. What we're working for is for her to be able to understand herself better, and to achieve control over some of her problem behavior. Some areas of concern for Rachel are to be able to have a job, to cook, to care for her body, and to learn how to go out in public and not get into trouble . . .

Task Force; Before, you answered an unanswerable question — what makes a homelike environment -- better than anybody I've ever heard. Now the sequel, which is even more unanswerable: How much of the help that you believe is necessary for a developmentally disabled person to grow and thrive in a home or home-like environment can be bought with real hard cash?

Susan: A LOT OF IT! Money is the key, it really is. If I'd have had money when my children were young, they would be in an entirely different situation now — entirely different. Look at severely disabled people - or any disabled person - who grows up with the conveniences, the tutoring, the things that money can buy - even friends. Money can actually buy people to come in and show concern for their well-being.

Now, hand-in-hand with money goes the responsibility of using it to hire someone who really cares and is going to be helpful.

Task Force: Now, the question that keeps coming up with the last. How does the cost of services the way you try to provide them or get them provided compare with the cost of the way most of the system provides them, especially in institutional care?

Susan: DEPENDING on whose numbers you believe, the cost of keeping Paul in a state hospital would be up to \$5000 a month, and about \$1800 to \$2200 in a residential facility. At home, he costs the regional center between \$250 and \$300 a month.

Task Force: So it's about 6 to 12 times cheaper to keep him at home?

Susan: Yes. It is so important to have just an extra pair of hands . . . Someone like Paul can "go through" three or four of me -- it takes an incredible amount of energy to give him the support and training necessary. There is the question of love, too. Sometimes people like Paul do not give back, in the expected way of a relationship — and that can hurt . . . and by having another person working with you you can reinforce each other when he isn't capable of giving it . . . Parents oftentimes "burn out". They get to a point where they just can't handle it any more and they need some backup, they need some support. They need someone to say "Don't give up . . . I'll help you." It's amazing how little it costs to get recharged . . . The critical point is this: other people may give up on the child — like the counselors and the social workers -- but the parents continue on, if they can find that reservoir of strength. Also, parents are willing to buck the system. Many counselors in the social field have a certain way of looking at things. Often, throughout the years, the advice I've gotten is to place my children -- and now, to place them as adults . . . And I'm told that a segregated school is a fine place in which to be educated -- but you know they only say that because it is convenient, the easy way . . . and they're dealing with the masses . • •

One of the ways money could be spent (better even in good home care programs): let us stop spending money training parents to be their children's psychological counselors and aides, and instead spend the money to hire people to support and co-teach with the parents. I don't want to be the sole trainer anymore. I want other people involved who can do some modelling, so the parents can step back and not "be" everything to the children . . .

I really think that if we are going to do something to make it possible for parents to keep disabled children out of institutions we must give them that other pair of hands, that other voice . . . Look at Rachel. She is coming to the point where instead of being in "programs" all her life she is on the verge of being in the job market . . . and maybe she can make it if I can give her somebody who will work one-on-one with her, and set her up in learning situations . . . it just takes a little patience and creativity . . . Today, she spent some time in a day care center for little children, and she knew intuitively that that's the kind of place she could work and would want to work — she could be an aide to the teacher and . . . be an extra pair of hands.

A person with developmental disabilities needs someone that can go in and work with them starting on their level — with the most profoundly, severely handicapped person up to the highest functioning person — and I don't care if it takes six months or ten years. But it is ridiculous to think that every handicapped person can be trained in six months or even in eighteen months. It's utterly ridiculous but this program faces that all the time. "At the end of this period of time, you are going to make this person a functioning member of

society, all problems are going to be solved, and we have a paper here that can prove it to the state."

Task Force: Is that what the state means by the developmental model? Does IPP mean Instant Personal Program? (Laughter) If those are the expectations of your program why aren't the same principles applied in the institutions?

Susan: With the severely handicapped person, unless they have that "other person" working with them, their development stops. I have no question in my mind that if we had not had this program for Paul, where people came in around the clock, he would be in exactly the same place he was in four years ago. He didn't get off a chair four years ago. "They" say that by the time you're 18, if you haven't learned the basic things you never will. That's not so. How long it takes is another matter. But what is learning? — it's that PASSPORT INTO LIFE. When you quit learning you quit growing. You end up inside yourself in a quiet, fearful place.

Task Force: How do you get the message across that people can grow and change? When we're talking to the professionals, to the Governor's Committee on Employment of the Handicapped . . . or where they're saying that people with mental retardation can't have feelings? . . . when you go to meetings of groups of non-retarded handicapped people, that retarded people can speak for themselves — maybe somebody made a diagnostic error they say . . . so where do you learn how to make society learn?

Susan: Well I think it needs to be presented to them visually. Some people can't hear it and can't believe it. When people hear the things that Paul and Rachel are doing, it doesn't have the same effect as when they see it. And when other families with disabled children see it, see that this family can make it, then they begin to think "Well, we can make it, too." They need to see that there's no subspecies involved here, that we're all human beings, every last one of us . . .

Task Force: Isn't that like how the story of Helen Keller made some people understand?

Rachel." — she used to behave just identical to Helen Keller before that teacher broke through to her . . . True, there are some people who will always be profoundly disabled, like Paul, all their lives. Yet he can also be healthy, emotionally stable, be able to do small things for himself, be loving and giving and receiving, know how to smile when people visit — instead of screaming and crying and striking out and living within a shell. I think there are people like that for whom the options exist . . . I can spot kids who are within that shell, who are retarded unnecessarily. My feeling is that Paul is going to overcome that part of retardation and come to a new level of functioning. My feeling with Rachel is closer to the Helen Keller story.

. . . I wish the state were more flexible in supporting services like psychiatric counseling for people like Rachel. They support the principle that she needs training to be a retarded person, but they do not recognize the fact that she may have emotional problems . . . It's a real hardship.

Task Force; That's one of the things we've discussed in this group. There are some little behaviors in some of us - some little hang-ups — that have kind of gotten in the way even when we're functioning at a community-based level — things that can prevent us from figuring out some things and making some decisions . . . so where do you go for help like that? At the moment the only place they'll talk to you is at the regional center, but they only deal with retarded people, so you gotta be careful that the kind of help you get won't be retarding, but help you be more normal. It's a problem . . .

Susan: What do we want from life? We want to feel that we fit. If you don't fit what do you become? — A MISFIT . . . I'm really angry when I read about people who are being molested, sexually abused, in some "facility", and then have people coming to my home recommending that I place my children in a "facility", maybe in a place just like that . . . People have motives for helping and sometimes they're good and sometimes they're not too good, but I don't think we can take for granted that there aren't any people (in facilities licensed or recommended by the state) who won't prey on people . . . After all, isn't there a saying: "People live in homes and not facilities?"

. . . (While we're on the subject) I think parents have been preyed upon for too long . . . by having to supply all the services if they want to keep their children out of those horrible institutions. And I think at some point the parents have to stand up and say "I cannot do this alone. I am not willing to do this alone. It is not healthy for me . . . or my children for me to do this alone." They need other people, people in the community . . . but I don't believe there are any parents that don't care, it's just that they wear out. It's a two-way street - if the community - society - wants the children to stay in the home or come back to the home, then the community should buy the support services to do that . . . • It's a lot easier to take an emotionally disturbed child or a child with developmental disabilities (that lead to violent behavior) and do interventions on the spot in the home, as those behaviors arise, than to try to deal with those behaviors later after they become ingrained.

. . . It does not make sense who money is being spent these days when we know better ways of doing things . . . After we stop the nonsense then we are able to do the things that work . . . Usually people with disabilities are not looked at for what they can possibly do for themselves — they're looked at in terms of what they cannot do. I'm constantly bombarded by the feedback that I'm not looking at my two "realistically" — or "Have you considered the fact that this kid here can't even crawl across the floor, and you're wanting him to walk room to room —

don't you know that isn't developmentally proper?" . . . and here he is walking all over the house AND THEY DONT EVEN NOTICE!

. . . But I'll admit that as a parent I make some of those same developmental mistakes, too. I used to think that Rachel had to brush her teeth, share her cookies, and smile before she could have a relationship with a young man . . . I have learned that she's lonely, that she has these feelings inside her, that she wants somebody besides her mother to share her life with — that's reality. And at some place I have to accept reality or go with how others see her in her limitations — what would you call it — brainwashing?

Task Force; You're the parent so you teach. But we're teachers, too, in our way . . . This doctor tells my mom — and that's why I hate the tests, because the doctor puts his feet up on the desk and he looks at me and I know I don't have a chance — and sure enough, he says to my mom "Your daughter will never be able to take care of herself in the home, you're even gonna have to give her a bath" — and then my temper comes out of me and I say "You don't know what you're talking about . . . • You're not God, you didn't create me and something in my gut tells me you don't know what you're talking about and . . . one day I prove you wrong." . . . And I say to that doctor "How many people are under lock and key because you think you're God with all that power?"

. . . But how many parents go to doctors (or other people like that) and then they do things to their children because those people say "I know best." The test they give of a human being does not show what there is inside and they don't give you a chance. I HATE THAT. They don't give you credit for any ability you have inside.

**PART TWO:
SELF-ADVOCACY ORGANIZATION
AND TRAINING MODEL**

**CHAPTER 11 :
INTRODUCTION AND BACKGROUND
OF THE PLAN**

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The Consumer Involvement Subcommittee of the State Council on Developmental Disabilities defines self-advocacy as:

A process through which consumers influence the decisions affecting their lives and thus promote continuous development, self-determination and choice.

It defines a self-advocacy organization as:

An organization in which the majority of officers and members are consumers. A self-advocacy organization also addresses the issues and needs confronting consumers as seen by consumers.

People First of California, which clearly meets both definitions in structure and function, agreed, as part of the contract under which this report has been prepared, to develop a plan or "model" for helping more consumers to develop self-advocacy skills, and to help such consumers form self-advocacy organizations.

In looking back over the life experiences of its own members and of the people who were interviewed in the course of preparing this report, the task force concluded that the most addressable need of people with mental retardation for gaining the strengths and skills needed to improve

their own circumstances lies in organization. The most important response to this report's finding that much of the developmental disabilities service system is failing to live up to the requirements of the Lanterman Act and therefore is acting as a "retarding environment" is to generate effective counterforces which will move the system toward greater compliance with the law. This job requires hard and thoughtful work in organizing and training self-advocacy groups.

The task force is aware that this finding touches on concerns expressed by members of the State Council on Developmental Disabilities and some area boards that the growth of the consumer advocacy movement in California has been relatively slow. To those people, whose positions put the responsibility on them for backing advocacy of all kinds for the developmentally disabled, the task force can only say: It won't happen until somebody goes out and does it.

Background of the Organizing and Training Plan

In various places in this report, we have noted how the experience of doing the work required by the contract with the State Council on Developmental Disabilities created a kind of transformation in the task force. It is not going too far to look at that transformation as the emergence of a "new family" — a family which made it possible for some members of that task force to discover what they had never found in their biological families, or in the places they lived when they left home.

As individuals, perhaps most of the task force members look back on their pre-independent lives with a sense of pain and rejection and anger. Even in their independent living arrangements, few are financially independent because of a lack of self-supporting jobs or the training needed to take advantage of job opportunities when they come along. Some task force members are still being pressured by their regional center counselors to return to sheltered workshops or to segregated adult schools.

Except for one member who drives, disabled task force members are limited in mobility by an inadequate public transportation system and an even more inadequate special transit system for the disabled. This is not intended as an attack on either system, which clearly are trying to do their best in a society that simply is not oriented to meeting the transportation needs of people who don't have automobiles at their disposal.

In short, independent living is distinctly not an end in itself where the quality of the life lived is at issue. This is discussed in Chapter 4. What has made a very important difference in the lives of the task force is the extent to which that social isolation in independence has been significantly overcome by membership in People First. For the task force members it has produced a sense of belonging and participating in a group that comes close to the idealized family some never experienced. It has become an important way station on the road to further growth out of

retardation, perhaps an essential one — just as some physiologists and neurologists argue that until a person has learned to crawl right he'll never learn to walk right.

One of the things the task force learned in its travels is that this feeling does get across to other disabled people — the more so the closer they are to independent living themselves. One of the frustrations of the data-gathering field trips was that the task force began to recognize the readiness — even, one might observe, the hunger — of so many of the people visited for being guided to next steps of organization, where they could explore new ways of working on improving their own lives and helping each other. The frustration of the task force came from not being able to follow up on that readiness, knowing that its own symbolic message of hope to those people would not be enough. The task force knew that follow-through with consumers helping other consumers to organize is the only answer.

At one place visited, the staff had been through an unfortunate bad experience with some other People First members, and was openly hostile to the task force and to the idea of the visit. The task force, to its own surprise and pleasure, was able to leave that place not only having healed the old angers and having made friends with the residents and at least some of the staff, but actually having gotten the impetus going for a new People First chapter.

All of these experiences were the subject of many hours of review, conversation and debate by the task force as it decided what should be

said in this report. The conclusion was unanimous - consumers can and should organize consumers. If done right, the new organizations can do two critical things: (1) they can become a "new family" for members who can benefit from that experience in growing out of retardation, and (2) through that internal strength, exert a real external impact on the developmental disabilities system and the community.

Those conclusions and insights, and ideas about how they can be turned into action, are the basis for the proposed model for organizing and training self-advocacy groups.

EDITOR'S NOTE: The reader may notice a change in tone and complexity of the balance of Part 2. Although the consumer members of the task force played important roles in discussing and critiquing the self-advocacy training model, it is proper to say that the advisors to the group were the basic active force in visualizing and articulating the model. This is reflected in the style of the presentation.

**CHAPTER 12:
SELF-ADVOCACY ORGANIZATION
AND TRAINING MODEL**

CHAPTER 12: SELF-ADVOCACY ORGANIZATION AND TRAINING MODEL

This entire very long chapter may be viewed as a single, complex recommendation which can be worked on jointly by the State Council on Developmental Disabilities, the Organization of Area Boards, and any or all individual area boards.

The model described would probably come under the category of experimental or pilot project. It envisions that an area board interested in the concept would select a community where there is no consumer advocacy group to be the locale of an organizing and training effort to create such a group. The organizing and training would be done by a special training unit of primary consumers with additional assistance as required. One of the primary goals of the project would be to leave the new group with the skills and motivation to be able to go out and replicate the organizing and training process itself, a kind of group version of "each one teach one".

A. THE TRAINING UNIT

The organizing and training unit would consist of four to six primary consumers and two or three non-disabled advisors. This unit would be very consciously patterned after the task force that did this report. It is essential that the training unit be very experienced and that it have evolved a feeling and bonding within itself that is what has been described as "the new family".

It would be useful if the primary consumers in the training unit represented a range of developmental disabilities both as to kind and degree of severity. To the extent possible, they should be living examples of how it is possible to overcome or compensate for biological impairments, and of how people can free themselves from the artificial hindrances of the retarding environment. This will give the training unit the advantage of providing the trainees with models as well as with information.

B. INITIAL AREA BOARD RESPONSIBILITIES

It is assumed that an individual area board will be the sponsoring entity of the proposed project according to the provisions of the Lanterman Act:

Area boards shall encourage and assist in the establishment of independent citizen advocacy organizations that provide practical personal services to individuals with developmental disabilities. Such citizen advocacy organizations shall be established for the purpose of recruiting, training, and assigning volunteers to work with individuals with developmental disabilities to assist them in using community services and participating in community activities. (Welfare and Institutions Code Section 4592.)

There are some immediate requirements the area board would have to take care of to enable the establishment of an organizing and training effort within its boundaries:

1. A community would have to be selected.
2. Funding to cover the costs of the project would have to be arranged.. Area boards might this in their agreement with the State Council on Developmental Disabilities.

3. The area board, working with a training unit subcommittee, would have to locate and "empanel" a group of potential advisors to a self-advocacy group, based on criteria developed by the training unit. This would be the potential cadre of the volunteer group described by Section 4592. Section G is devoted to this extremely critical matter.
4. The area board would have to identify the living and working places in the community where the potential primary consumer members of the advocacy group could be recruited. In this matter, protection of the confidentiality principle is of utmost importance. Protection of civil liberties is one of the objectives of the organizing effort, and confidentiality is one of the fundamental rights of recipients of public services. It will therefore be the responsibility of the area board to obtain all necessary clearances, waivers, or whatever is required to assure that client confidentiality rights are honored. Where this cannot be accomplished, the training unit will simply have to be denied access to facilities or individuals.
5. The most important "environmental" requirement is for the area board to find a place to meet that will not remind people of a sterile classroom or a devalued "recreation" or "all-purpose" room that can be found in most institutions for the developmentally disabled. Locating a comfortable, tastefully furnished, commodious, accessible place in a building that is not associated with the "system" will be an important and perhaps

difficult – but absolutely essential – task for the area board. Consideration might be given to locating a permanent headquarters for the organization. On the other hand, getting such a place for the long run could be an important project for the group itself after it is established. The point is that whatever the long run brings, the initial training should be associated with a place that overturns the negative images and experiences of institutionalization. Without that, the goal of beginning to counter the retarding environment will be much harder to achieve.

SELECTION OF THE TRAINEE GROUP

Section G, which discusses the importance of the advisors to the new group, recommends that the advisors be selected provisionally by the training unit. These advisors will receive some preliminary training through working with the training unit to identify an initial working core of primary consumers from the people made accessible by the area board. Most of their training, however, will come from participating in the same curriculum that is designed for consumers after the core group has been formed.

The process of enlisting primary consumers in the core group of trainees has a very high potential for becoming a matter of a little intuition and a lot of luck. Self-selection will be the first factor. Simple logistics will be critical – who can get to the

intensive set of meetings and commit not to miss any, how they can get there, and so forth.

It will be important for the core group of consumers to have fairly well-developed communications skills, since the training will be concentrated and time-limited, and a lot of effort forced into overcoming communications barriers will be counterproductive. Working with people who have severe communication problems will be one of the jobs the core group will want to undertake as it establishes itself as a helping force in the community.

If there is a single most important criterion or characteristic to take into consideration in whatever screening may take place, it is trying to sense whether an individual is interested in learning about self-advocacy and leadership in what usually ends up as a selfless and often thankless undertaking, or whether the person is largely motivated by wanting to be a "big shot". On the whole, it is probably worth going for somebody who is assertive and strong, and hoping that the group process will create a leader. On the other hand, at any time that somebody turns out to be intolerably disruptive, the group will have to figure out how to get that person to delay further participation until the group has learned how to work constructively with those kinds of relationship problems. If such problems turn up while a group is just getting itself together, it needn't be a disaster — it can lead to a quicker development of a sense of co-

hesiveness, and it can teach people the distinction between narrow ego satisfaction demands and genuine leadership for service.

D. TRAINING SCHEDULE

It is assumed that the training unit will not originate from or necessarily near the community selected for the project. Therefore, the schedule needs to permit the training unit to return home after the first few days of training. Even if distance were not a factor, it is the experience of the contract task force that the type of curriculum proposed is of such an emotionally intense nature that avoiding "overload" must be a serious, conscious consideration.

The initial training schedule is therefore recommended as blocks of* four full consecutive days per week for each of two consecutive weeks, with a four or five day interval between the blocks.

The second phase of the training would occur in a three or four day block about five or six weeks after the initial phase. This will be devoted to review of what has happened in the intervening time, consolidating insights gained and relating experiences to abstract principles, and examining problems encountered.

Finally, the task force believes that the training unit must be willing to accept responsibility for being "on call" to assist the

new group with serious problems that arise in the early months. This must have an emergency flavor to it – both groups must restrain themselves from fostering an inappropriate dependency – but the availability of problem-solving expertise in a crisis can be a legitimate service to a new group while it is struggling to establish its character and identity.

E. CURRICULUM

Although some rather specific items will be discussed in this section, it must be understood that this is not a formal syllabus of a course of instruction. It is rather an attempt to show how the stage should be set, to suggest ways of achieving a tone and a feeling that will begin changing a collection of individuals with developmental disabilities into an effective and independent advocacy organization.

The basic objectives of the curriculum would be:

1. to raise the consciousness of the trainees about the critical issues;
2. to impart information and skills that can be built on in creating an effective organization; and
3. to stir up the motivation to keep on learning and growing for one's own sake and to be able to help others.

To accomplish these objectives, the way information is presented will have to keep people interested and enthusiastic. Great care

needs to be taken not to call up memories of a demeaning or devaluing experience in the traditional education system.

In preparing this proposal, the task force found some outstanding examples of thoughtful, well put together documents on self-advocacy for people with developmental disabilities. A list of these is included in the appendix. They cover the meaning of ideas like normalization and other words which have become the special language of people who are involved in citizen advocacy for the developmentally disabled. Some of these documents do a good job of explaining rights and responsibilities. They help people understand how to work at getting the service system to work for them. They offer "how-to" guidance in being assertive, in the technical aspects of forming organizations, in planning and conducting meetings, in testifying before important groups, in fund-raising, in educating the community, in negotiating with public and private agencies outside the developmental disabilities system such as transportation agencies, and many other useful things.

The training unit would have to spend a great deal of time in advance preparation going over these materials — including the Lanterman Act and related laws — deciding what to use and how to use it, what to make available to the new group as basic source documents, what to try to boil down, at what point in the training to present what material, and so forth. This is going to be a difficult task,

because book-work really has to be kept to a minimum - but it is essential.

One of the enormously important parts of the training program must be devoted to helping people with developmental disabilities get to know as much as possible, as clearly as possible, about what's going on inside them, and what is not working the way it works in non-disabled people. Perhaps a whole day, or some part of every training day, should be devoted to this issue. People who don't know about their disabilities, or are afraid of facing them, often are unable to be successful in overcoming them or learning how to compensate for them. Being able to "know thyself" is often very hard. Several members of the task force still have a difficult time just making themselves say the words "mental retardation". But as they learn to say the words without giving in to the memories of the hurtful way the words might have been used by insensitive people, they find they have achieved new strength and new progress in outgrowing and outmanoeuvring the retarding environment.

As much as possible of the training should occur in a practical, active way. There is a book called ANDI - which comes from the first letters of "A Normalization and Development Instrument" — that gives ideas about how to look at places where developmentally disabled people live and work in order to help people evaluate whether objectives such as those found in the Lanterman Act are being paid attention to in these places. Spending a substantial amount of time on (a) working

on understanding the ANDI concepts, (b) going to one or two places where the ANDI system could be applied "hands on", and (c) going over the experience afterwards, would be an excellent way of learning about many different things.

Likewise, spending a fair amount of time preparing for a day-long meeting with the area board in which the new group would play host, provide lunch, and discuss a variety of issues of mutual interest, such as consumer representation on committees, cooperative activities in community education, and a host of other concerns, and then more time spent on reviewing the experience of that meeting, could cram years of learning into two days.

Part of the initial training period would also be devoted to working out some specific goal-oriented tasks that could be undertaken by the new group in the interval between the first two weeks of training and the follow-up week. Likelihood of success would be a strong consideration in this planning process. For example, meeting with the local newspaper editor and television news people to ask for coverage of the new group and possibly a supportive editorial might be a rewarding effort. Meeting with the local Private Industry Council (PIC) to ask for assignment of a reasonable number of on-the-job training slots to people with developmental disabilities is another possibility. Local conditions offer other possibilities. For example, one of the groups interviewed by the task force had been

successful in negotiating safer crosswalks in the vicinity of their residence with the appropriate municipal agency. Setting up some integrated athletic or social activities with the YMCA or similar organizations might be feasible.

The key, as noted, would be the strong prospect of success. "Rigging" for success would be inappropriate and would not bring real strength to the group. But deciding to badger a financially pressed public transit agency to run buses in certain areas at off hours for the convenience of a very few consumers would probably lead to failure and even ill-will — not the objective of the early stages of learning how to be a self-advocacy force.

FACULTY

The importance of primary consumers as teachers and role models to the trainees is critical. Training unit consumer members will need to accept responsibility not only for the content of what they take part in presenting, but also for becoming conscious of the impression and impact they make as individuals. For example, as self-advocacy "how-to" manuals point out, if learning how to listen is an important self-advocacy skill because it enables you to understand where the other person is, then helping people to learn how to listen takes instruction from somebody who knows how to listen.

It is not realistic, however, to expect as ambitious a project as is outlined here to be successful without substantial involvement of people who are professional communicators. Over the years, People First members have encountered many individuals who, besides being truly dedicated to helping developmentally disabled people make a better life for themselves, are also extremely able and exciting teachers. People like this have a knack of bringing issues to life and making concrete reality out of abstractions.

At a recent meeting of People First, a friend came to talk about understanding the law and legal rights. Rather than reciting a list of rights enumerated in the constitution, he asked:

How many people here know they have a right to vote?

(All hands were raised.)

How many people here know that there's an election next month?

(About half the hands went up.)

Well, tell me what good it is to know you have the right to vote if you don't know when there's an election?

That provocative kind of questioning can lead to a very valuable raising of consciousness. When managed by people who understand the issues and know how to "go with the flow" and not let things get bogged down in a rigid lesson plan, remarkable things can happen. In particular, that kind of experience is what stimulates people to want to learn more.

Most so-called normal people will remember one or two — if they were very lucky, maybe three or four — teachers who stimulated that kind of excitement and enthusiasm for learning, over a period of twelve, sixteen or even twenty years of schooling. People with developmental disabilities have had far less opportunity, if any, for such growth provoking educational experiences. Imagine, for example, the impact of a person with thorough expertise in the medical aspects of mental retardation and the skills of an entertainer. Imagine what might happen if two, three or four such people dropped into the lives of a group of people with developmental disabilities within a two-week period. Just getting an answer might be worth the entire experiment:.

G. IMPORTANCE OF THE ADVISOR

The advisor or advisor team is crucial to the success of the effort. Advisors will provide the primary source of direction in the preliminary stages of establishing a self-advocacy group. Advisors will be the critical non-disabled friends, mentors and role models, an early source of moral and emotional support and assurance to members of the new group. They must have the sensitivity not to overwhelm consumers or foster dependency. Their task is to promote growth toward independence, and to function, if necessary and appropriate, as a kind of cement in the bonding process that creates the "new family".

Advisors will have to expect and accept substantial demands on their time and energies. An advisor should be an unpaid volunteer to avoid the "social distance" that so often intervenes between consumers and people who are paid to do things for them. (The task force saw the "staff dining roan" and the "kids' dining room" everywhere.) On the other hand, if at all possible, an advisor's expenses should be defrayed so that no financial hardship is intruded into a relationship that is bound to have all the tensions it can handle without that.

The expectation is that advisors will be making long-term commitments. No one who is likely to be leaving the community in the foreseeable future should be considered except in very special circumstances. Likewise, although students may often be very helpful assistants to advisors, the idea of treating an advisorship as a practicum for purposes of studying the developmentally disabled is inappropriate to the point of the relationship.

The experience of the Capitol Chapter of People First in working with an advisor "team" of two, who happen to be long-term personal friends, and one of whom is a secondary consumer, has been exceptionally sound and successful. The sharing of advisorial responsibilities among

compatible people seems to reduce stress, provide additional depth to judgement and insight, and enhance continuity and informed back-up in emergencies.

The danger inherent in trying to establish such criteria for what makes a good advisor is that pretty soon it begins to sound like "old saints need apply". In fact, the last thing the project needs is somebody who wants to play God.

There are a few specific qualifications, however, which are of such extreme importance that an advisor who can't meet them would probably be bad for the job.

1. A Sound Value System

An Advisor doesn't have to have a great deal of specific knowledge about developmental disabilities or about the developmental disabilities system. But he or she must absolutely have a gut belief that "where there is consciousness it can be raised" - that everybody has the potential for further growth and development. There must be an understanding and belief in the primary task of protecting and nurturing the exercise of the civil rights and civil liberties of people with developmental disabilities as the indispensable ingredient of freedom and independence. There must be a resistance to the idea that any human being has the ability or the right to predict the limits to growth and development in another human being. In short, an advisor who will make a positive difference is one whose value system - as opposed to rigid ideology — rejects the implicit tenets of the retarding environment, a value system which will take the person to great lengths in fighting for the objectives of social and legal statements such as the Lanterman Act.

Procedural Flexibility

It might be acceptable for some rigidity in an advisor's values and beliefs, if there is fundamental support for good objectives. But there is very little room for rigidities in helping methods. An advisory must be able to know the difference between providing direction to a group and being a dictator, and be able to provide legitimate direction without fretting that this interferes with growth through "doing it by yourself". It can be observed that some of the best service providers are "eclectic practitioners" - that is, they don't confuse a purist belief system with procedural rigidity in pursuit of those goals. Whatever works in practice is acceptable as long as it isn't illegal or unethical. You can't get to normalization by institutionalized rigidities.

Avoiding Conflict of Interest

The essence of a self-advocacy organization is its independence from the developmental disabilities system. No advisor should be a service provider, or in any sense a part of the developmental disabilities system. This of course raises a hard question about "secondary consumers". Since self-advocacy involves the likelihood - some would say the inevitability - of conflict with the system - a secondary consumer might come under pressure from the system in such a conflict through the implied threat of retaliation by withholding services or the like from the primary consumer.

Exactly the opposite has been the experience in the case of the Capitol Chapter of People First. The secondary consumer/advisor has not had to depend on the system for assistance, therefore has not been in need of the system's good will. But the issue still can't be ignored. The requirement, if there is one, might best be stated as calling for a realistic minimum of potential conflict of interest, recognizing that some of the best advisors possible are secondary consumers.

H. ADDITIONAL ACTIVITIES FOR THE AREA BOARD

While the new advocacy group is being formed and trained, the area board can involve itself in additional tasks which can be critical to the eventual success of the organizing effort.

1. Information about the project should be provided to community agencies and institutions such as schools - and especially community colleges - service clubs, local governments (especially such programs as those under the federal Job Training and Partnership Act), special disability service programs (such as United Cerebral Palsy). These organizations and groups should be invited to establish liaison with the new advocacy group when it is functional. The good offices of the area board ought to speed and enhance this linkage process.
2. Influential individual citizens should also be advised. Those expressing willingness to invest time or resources in the new

group should be enlisted as an informal "power structure" support group, which may or may not wish to assume a more formal identity as the project matures. Such a group, or even a single individual, could assist the new consumer group to obtain access to community resources not reachable through the developmental disabilities system - for example, a member of the transit board could do more than the regional center in getting real problems listened to. Important technical services such as accounting and non-advocacy legal services could be obtained on a pro-bono basis. Most important of all, such individuals or groups could be invaluable in guiding and assisting the consumer group to develop a strong private fund-raising effort to keep it independent and self-sustaining.

3. A third special resource might be identified for possible link-up with the new consumer group. This is the well-known pool of energy, community spirit and expertise to be found in the population of senior citizens. The possibilities of a constructive, mutual support and respect relationship are worth investigating.
4. Finally, the area board might assist the new group to locate other advocacy groups of and for people with other kinds of disabilities. For example, the blind have long been a powerful self-advocacy force. In recent years, people with other physical handicaps have become increasingly effective in self-advocacy. Some of these groups could be extremely helpful to the new group, and perhaps join forces at some point in a coalition.

Given the foregoing broad but reasonably well-focused model for action, People First recommends that the State Council on Developmental Disabilities and the Organization of Area Boards meet and work together to initiate appropriate follow-up activities, such as determining where and to what extent funds might be found to establish such a project, preparing a request for proposal, determining if there are any area boards interested in becoming test areas, etc. People First will be pleased to assist in further developing this model in any manner within its means.

SUMMARY OF RECOMMENDATIONS

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RECOMMENDATIONS ABOUT THE STATE HOSPITAL SYSTEM

- Future planning by the legislative and administrative branches of California state government in the field of developmental services should focus on the complete phasing out of the state hospital system as rapidly as feasible and simultaneous with the phasing in of a comprehensive community-based system of services to meet the needs of every Californian eligible under the Lanterman Developmental Disabilities Services Act (Chapter 3).
- Funds to accomplish completion of the community-based service system as required by the Lanterman Act should be derived to the extent possible by diversion of funds from the state hospitals to the regional centers as rapidly as the hospitals are phased out, from sales of state hospital properties, and from savings realized in the transfer of programs and services from state hospitals to community-based and home-care programs (Chapter 3).
- Special programs for the community Habilitation of long-term state hospital residents should be given priority attention as part of the hospital phase-out plan (Chapter 4).
- The occasional state hospital-based service which is of such a high quality that it is drawing applications for inappropriate hospital admissions should be relocated outside the state hospital system and expanded statewide as rapidly as possible. The staff of such programs should be assisted in every way to stay with the programs,

including aid in becoming proprietors of such programs in the community (Chapter 5).

RECOMMENDATIONS ABOUT COMMUNITY-BASED PROGRAMS AND SERVICES

- Legislation should be enacted to require every person engaged in the provision of care and/or services to persons with developmental disabilities (including state hospital employees) to graduate from an approved course of instruction and training in the content and objectives of the Lanterman Act and related laws, including federal and state constitutional protections of citizens. The course should be put together by well-qualified educators with the advice and supervision of a panel of judges, members of the Legislature, and the State Council on Developmental Disabilities. This course of training should be made available to members of area boards and the State Council on Developmental Disabilities (Chapter 2).
- Public agencies responsible for service planning should join with groups of concerned consumers in developing creative reimbursement successful care and treatment services, and, as required by law, develop criteria which will eliminate contracts with service providers who consistently fail to assist their clients to achieve progress toward higher functioning (Chapter 5).

- The changing needs of primary consumers who are moving in ever-greater numbers from dependent to independent living arrangements should be fully and continuously reassessed by all parties, including the consumers themselves, who are involved in working toward successful social integration and economic independence (Chapter 4).

RECOMMENDATIONS ABOUT SERVICES TO FAMILIES OF PERSONS WITH DEVELOPMENTAL DISABILITIES

- The Lanterman Act priority for supportive services for developmentally disabled persons living at home (Section 4685 of the Welfare and Institutions Code) must be honored both in spirit and in letter by the regional centers. All forms of family assistance specified by that section of the law should be developed statewide and adequately financed. The Legislature should hold hearings on this matter at key locations statewide so that parents, care providers and other interested parties can make their views and needs known. The Legislature might also commission a study on this subject (Chapter 9).
- Regional centers need to develop larger, more effective outreach services to be delivered as soon as possible to families when they discover that a child has a developmental disability. The aid of primary and secondary consumers should be enlisted in developing and providing such services (Chapter 9).

- Regional centers should make available services to help primary consumers who have achieved independence re-establish supportive relationships with their biological families where possible and appropriate (Chapter 4).
- Services to families should include greater emphasis on independent living skills even when adult disabled persons are continuing to live in a family setting. Such persons and their families also need assistance in planning for the most home-like living arrangements for the disabled member in the event of the death or other incapacity of the non-disabled family members (Chapter 9).

RECOMMENDATIONS ABOUT VOCATIONAL ASSESSMENT, JOBS AND TRAINING

- Regional centers should be encouraged, helped and adequately funded to move away from reliance on the traditional system of sheltered workshops and segregated adult schools and into mainstream vocational development through on-the-job training and other more effective models of work training and preparation. The Joint Resolution of November 3, 1983, of the State Council on Developmental Disabilities and the Governor's Committee on Employment of the Handicapped to the State Job Training Coordinating Council provides a clear outline and plan for linkage with such mainstream services (Chapter 6 and appendix).
- The State Job Training Coordinating Council, in addition to implementing the recommendations of the November, 1983 joint resolution, should adopt a policy of having the interests of disabled people

be represented by disabled people, and should encourage Private Industry Councils (PICs) to seek out disabled businesspeople to serve and provide input (Chapter 6).

- All agencies involved in vocational assessment and employment development should cooperate to locate or develop tests and other instruments or techniques that will more thoroughly and adequately uncover and assess potential marketable talents and skills of people with developmental disabilities. Such indepth assessment should be utilized by regional centers to work with clients in developing Individual Program Plans (IPP) that properly meet the intent of the Lanterman Act (Chapter 6).

RECOMMENDATIONS DEALING WITH SELF-INTERESTS OF CONSUMERS

- The Legislature should appropriate funds or require the State Council on Developmental Disabilities to set aside funds to develop a consumer-usable version of the Lanterman Act and related laws and constitutional provisions of importance to consumers so that they can be fully apprised of their rights and responsibilities under the law. This material should be produced in whatever forms and with whatever communications devices are necessary and appropriate for use by persons with developmental disabilities. Persons with such disabilities should be involved to the fullest extent possible in the process of preparing such materials. Coverage should include highlighting of the legal rights and responsibilities of consumers,

the legal responsibilities of service providers and advocacy panels established by law, outcome objectives of service programs, and information on how consumers can find help to resolve problems with the developmental disabilities system (Chapter 2).

- The California State Council on Developmental Disabilities, if feasible in collaboration with such councils from other states, should compile an anthology of biographical success stories of persons with developmental disabilities. This biographical anthology should be prepared in whatever forms and with whatever communications devices are necessary and appropriate for use by persons with developmental disabilities. The effort should be kept current, perhaps by means of a yearbook. Such material should be used as an important device in educating the general public to the realities and potentials of persons with developmental disabilities. Data collected for this undertaking should be used for analytic purposes to attempt to determine what factors contribute to successful outcomes, and what factors appear to be hindrances to success (Chapter 8).
- The California State Council on Developmental Disabilities should initiate a nationwide collaboration with other state councils to develop an Individual Independence Account (IIA) plan modelled after the Individual Retirement Account (IRA) available to taxpayers. The IIA should be available to persons with developmental disabilities who have potential for independent living and/or substantial progress toward self-support, who are recipients of Supplemental Security Income (SSI). This program should be simple, flexible and

well-publicized, and should supercede existing complex, over controlled and unpublicized income and resource set-aside plans (Chapter 7).

RECOMMENDATIONS ABOUT ORGANIZING AND TRAINING CONSUMERS FOR SELF-ADVOCACY

- Chapter 12 is essentially a lengthy set of recommendations directed at area boards working with the assistance of the State Council on Developmental Disabilities and the Organization of Area Boards. It sets forth an action plan pursuant to which a special training unit of primary consumers, assisted by advisors and education or communications specialists, would organize and train groups of consumers to become self-advocacy organizations. One of the special objectives of such a project would be to enable the new group itself to replicate the process, leading to a more rapid expansion of self-advocacy activity than has been experienced in the past.

APPENDICES

APPENDICES

SUMMARY OF APPENDICES

- Appendix 1: Summary of California Developmental Disabilities State Plan, 1984-86
- Appendix 2: Additional Unmet Needs Comments
- Appendix 3: Keeping the Promise of the Lanterman Act: A Report of the California Assembly Office of Research
- Appendix 4: Resolution to State Job Training Coordinating Council
- Appendix 5: "PASS" Regulations and Administrative Guidelines
- Appendix 6: Self-Advocacy Bibliography
- Appendix 7: A List of Reports of the State Council on Developmental Disabilities Which Relate to Recommendations in This Report
- Appendix 8: Lanterman Developmental Services Act
(Available upon Request from Council Office)

APPENDIX ONE

STATE PLAN SUMMARY

PREPARED FOR THE STATE CONFERENCE OF PEOPLE FIRST, INC.

WHO ARE PEOPLE WITH DEVELOPMENTAL DISABILITIES? (State Plan - Part I)

Federal law says that people with developmental disabilities are persons with a severe and permanent disability that began before the age of 22. The federal law says that a developmental disability seriously limits the person from doing things in three or more of the following everyday activities:

1. Being able to take care of yourself.
2. Being able to understand what is said to you, and to make people understand when you speak to them.
3. Being able to learn.
4. Being able to walk or move around by yourself.
5. Being able to decide for yourself what you want and don't want.
6. Being able to live by yourself.
7. Being able to earn money so that you can support yourself.

WHAT IS THE STATE COUNCIL? (State Plan - Part I)

The job of the State Council on Developmental Disabilities is to advocate for the basic rights of people with developmental disabilities, to decide how services to persons with developmental disabilities should change and develop in California, and to make sure that services change and develop in the way that the Council decides. To do this job, the Council decides on policies (directions), plans for changes, advocates for those changes, and tells the State when it is doing things which don't help those policies.

Council members represent many groups of people interested in services to people with developmental disabilities. Council members include consumers, parents, and officials who make decisions about services. The Council makes its decisions by getting advice from committees, holding meetings, and collecting information from area boards, regional centers, and other groups (like People First). The Council also sometimes has contracts to help them figure out very difficult problems (like the People First contract).

WHAT ARE THE COUNCIL'S BELIEFS? (State Plan - Part I)

Basic Beliefs

1. INDIVIDUAL DEVELOPMENT

All people, including those with the most severe disabilities, can develop new skills and abilities, no matter how small that development may be.

2. INDIVIDUAL RIGHTS AND PROTECTIONS

Service Rights - State and federal law says that people with disabilities have the right to get services that will keep them healthy, help them to develop as much as they can, and meet their housing needs.

Protections - People with developmental disabilities have the right to be protected against laws, policies, or practices that discriminate against them and none of their rights can be taken from them without first going through a legal process.

Service System Goals

1. PREVENTION

Local, state and federal agencies must do whatever they can to reduce and/or eliminate those things that are suspected or known to cause developmental disabilities.

2. INTEGRATION AND INDEPENDENCE

People with disabilities must be given the opportunity to be a part of the community and to live as normal a life as they possibly can.

The State of California must make sure that programs are there to meet the needs of persons with developmental disabilities, no matter how severe their disability is or how old the person happens to be.

4. SERVICE QUALITY

In providing services, the easiest and cheapest way of providing that service should not be considered more important than providing a service that upholds standards of decency, respect, safety, health and pleasant surroundings.

HOW WILL THE COUNCIL PROTECT AND ADVOCATE THE RIGHTS OF PEOPLE WITH DEVELOPMENTAL DISABILITIES? (State Plan - Part II)

The Council will spend most of its job to protect and advocate rights on the following problems:

RIGHTS

1. To what services are people with developmental disabilities entitled?

The Council wants to make sure that people with developmental disabilities have a legal right to needed services.

2. Wages paid to clients in sheltered workshops and work activity centers.

The Council will do a study on the wages paid to persons with developmental disabilities who are in sheltered workshops and work activity centers in California. Also, the Council will study the recommendations made by the U.S. General Accounting Office for changes in the laws that says how much these persons can be paid. Once all this information has been gathered and studies, the Council will then make its own recommendations about workshop and work activity pay.

3. Basic protection against discrimination.

The Council will review any suggested changes to federal law which protect the rights of persons with disabilities. Also, the Council will make sure that the state law that protects the rights of persons with disabilities is enforced. The Council will also support the activities of groups (like People First) who are working to protect these rights.

4. Protection against discriminatory care for infants with disabilities.

The Council will review and speak against proposed laws that would discriminate against or hurt babies with developmental disabilities.

5. Physical access to buildings.

To protect the rights of persons with disabilities to be able to move about in the community, the Council will work for more accessible buildings.

6. Access to generic services.

The Council believes that those state agencies that have the responsibility to serve the general public also have the responsibility to serve persons with developmental disabilities. The Council will do whatever it can to be sure that those agencies meet their responsibilities.

7. Access to public transportation.

Persons with developmental disabilities should be able to use public transportation. The Council will support laws which make sure that buses have wheelchair lifts.

8. Right to a free and appropriate public education.
The Council will review state and federal laws to make sure that children with disabilities do not have their right to special education taken away.
9. Access to employment training and placement services for adults.
The Council will work to make sure that some agency is responsible for job training and placement of adults with developmental disabilities in regular jobs.
10. Access to non-vocational education/developmental training for adults.
The Council will work to make sure that some agency is responsible for education and living skills training for adults with developmental disabilities.
11. Access to essential medical care.
The Council will collect and give information to the Legislature and the Department of Health Services about any changes to the Medi-Cal law that would hurt persons with developmental disabilities.
12. Access to community residential neighborhoods.
The Council will work against any legislation or local community actions which may stop people with developmental disabilities from living in those parts of the community that most people live in.
13. Equal employment opportunity.
The Council will review suggested changes to the federal laws that protect the rights of persons with disabilities to work.

DUE PROCESS PROTECTIONS

1. Use of human subjects in research.
The Council will work with the Department of Developmental Services in writing these regulations to protect people with developmental disabilities from being treated badly in research projects.
2. State hospital admissions.
The Council wants to make sure that people with developmental disabilities are not placed in state hospitals when they do not really need or want to be there. The State Council will support laws that say how, why, and when a person can be placed there.
3. Individual program planning.
An Individual Program Plan (IPP) is written for every person with a developmental disability who is a client of a regional center. In this IPP is listed all the services that the person needs to develop and live as normal a life as possible. The Council will do all it can to make sure that services are based on the needs of persons with developmental disabilities.

Fair Hearing and Aid-Paid-Pending Appeal.

When a person with a developmental disability is told that they will no longer receive a particular service, they have the right to ask for a "fair hearing". They also have the right to continue receiving the service until a final decision comes out of the fair hearing. To protect the fair hearing rights of persons with developmental disabilities, the Council will help in developing training materials and interim guidelines on how to use the current fair hearing process. Also, the Council will watch the development of regulations for regional centers and state hospital fair hearing processes.

Substitute consent for sterilization.

The Council believes that government should not be able to stop a person with a developmental disability from having children, without first going through a very thorough legal process. This process should include finding out whether or not the person knows if they want to have children or not. The Council has developed a very detailed process that will make sure that the person's rights are protected and will try to get support for this process from people with developmental disabilities and advocacy groups.

Diversion from the criminal justice system.

The Council believes that any person with developmental disabilities who commits criminal acts should receive treatment and rehabilitation rather than going through the criminal justice system. State law already allows this to be done. The Council will support laws that continue these programs and will educate policemen about the special needs of people with developmental disabilities.

Protection against inappropriate or unauthorized application of physically restrictive procedures.

The Council realizes that under certain circumstances it may be necessary to physically stop a person with a developmental disability from hurting them self or someone else. The Council also realizes that the person being stopped could also be hurt by the people that are stopping him or her. Because of this, the Council has developed a policy on stopping a person from hurting themselves or someone else. The Council will try to make sure that the other agencies develop the same types of policies.

8. Access to culturally appropriate services by ethnic/cultural minorities.

The Council believes that there are people with developmental disabilities who are also members of minority groups (Black, Asian, Hispanic, etc.), who are not getting services or are not getting the right kinds of services. To help them, the Council has contracted with the State Hispanic Council to find out about the service needs of persons with developmental disabilities in the Hispanic community. Also, the Hispanic Council will develop a needs process and a book to help other groups.

HOW DOES THE COUNCIL WANT TO MEET ITS GOALS FOR THE SYSTEM?

PREVENTION (State Plan - Book III)

The Council doesn't want people to have a disability if there is a way to "prevent" the disability. Parents and new-born babies should be helped so that the babies can be born and grow up without special needs. The State Council will help by working with others on the following jobs:

1. Training professionals to know more about disabilities and their causes.
2. Training parents to know more about disabilities and their causes.
3. Collecting information.
4. Making sure that parents and children have the best information and services.
5. Getting rid of those things in the air and water that cause disabilities.
6. Putting someone in charge of prevention in California.

INTEGRATION AND INDEPENDENCE (State Plan - Book II)

Since so many things need to be done to improve the lives of persons with developmental disabilities, and since there is a limited amount of money to do those things, the Council has had to decide which is more important. So, for the next three years, the Council has decided that Integration and Independence will be the main goal, especially to make sure that people with developmental disabilities live in the most integrated and independent situation.

The Council wants people with developmental disabilities to move from big isolated places, like state hospitals, to smaller, more home-like places in the community - if that is best for them. The problem is that there are not enough of the right kinds of places to live for all the people who do not really need to be in the state hospitals to move. To change this, the Council will first identify those people who are now living in state hospitals, who do not really need to be there. They will then find out why these people have not been able to move. When all this has been done, the Council will work with other agencies

to make sure that every person with a developmental disability has the chance to live in the type of place that best meets their needs.

Specific issues to be worked on for reducing usage of the most restrictive alternatives include:

1. Service needs assessment of individuals currently inappropriately placed in large skilled nursing and intermediate care facilities.
2. Elimination or mitigation of disincentives to movement from large facilities and creation of incentives for community placements.
3. Development of areawide plans for alternative community living arrangements as required to move persons identified as inappropriately placed in large congregate residential facilities.
4. Identification of resources necessary for service development to reduce inappropriate placements in large congregate residential settings.
5. Implementation of plans for development of alternative community living arrangements for persons identified as inappropriately placed in state institutions.
6. Piloting of innovative community residential alternatives which target the needs of individuals on referral from large congregate facilities.
7. Transition of training personnel from institutional to community settings.

Specific issues to be worked on for expanding usage of the least restrictive alternatives include:

1. Conducting of research to determine those factors (including service and amounts) which are critical to successful residence in normal or near normal settings.
2. Elimination of fiscal disincentives and creation of fiscal incentives for maintaining children at home.
3. Enhancement and development of support services for families with minor children and in-home support services for adults.
4. Enhancement and creation of home-like alternatives to the natural home for children.
5. Development of skills and provision of incentives to promote more independent and normal lives.

SERVICE QUALITY (State Plan - Part IV)

The Council will be working on the following issues for service quality:

1. Regional center management information system.
2. Community residential care standards and rates.
3. Training of level of care staff in state hospitals and community residential facilities.
4. Day training activity center standards and rates.
5. Standards for state hospitals.

AVAILABILITY OF SERVICES (State Plan - Part IV)

The Council will be working on the following issues that are important for availability of services:

1. Defining eligibility for services.
2. Assessment of unmet service needs.
3. Service development.

Writing a summary of the state plan is hard, but the Council hopes that this summary will help People First to understand that the Council wants to help consumers live a better life. The Council feels that people with developmental disabilities are as important as anybody else. They have the same rights as people who do not have disabilities. They are important members of the community. By putting all its beliefs, plans, and goals in the State Plan, the Council hopes that all people will understand more about what the Council thinks is important.

APPENDIX TWO

List of comments on unmet needs

Living places:

They treat us like kids
They scold you and make you stay in your room
Not enough chance to be alone
Afraid of staff
Afraid of other residents
Afraid to go outside
Want my own place
Why are the neighbors afraid of us?
They treat us like we're all the same, but we re not
Not enough staff
Staff not trained good enough
Consumers should run places to live for other consumers

Work:

More choices of jobs to learn
More choices of jobs to do
More jobs
Better pay
We need to be out of segregates training programs
Why can't we do peer counseling?
On-the-job-training
Why can't they teach us to run a business?
They have such low expectations of us
They make us afraid to leave the workshops

Education:

You can't win – if they put you in special classes, the rest of the kids treat you like you're different and dumb; if they put you in regular classes with those kids, it's hard to keep up, so how do they treat you?
One good teacher can save your life
People were surprised when I was good at something
The regular kids didn't like school either
I wish I could go to classes with nondisabled people now that I'm not embarrassed any more
The books with the LARGE PRINT are best
They need to help people who can't read learn anyway
People who don't have speech or don't speak good need more help
They worked with us individually – that was good
My main problem was they didn't help me when I was young

Health and Medical Care:

If I don't get so mad I don't get as many seizures. This place
helps me learn how to control my temper
I wish I knew more about what's the matter with me
Trying to help me not to lose Medi-Cal all the time makes my
social worker cry, and me too
Some of them treat you like you're just a thing
It's good the way they teach you how to take your pills by
yourself, but some of the medicine makes me feel bad
My doctor is so nice I wish I could get a job working there
They won't give you counseling for emotional problems
They don't think we have feelings

Access to the Community:

Better public transportation
More buses at night
They should teach us to drive
We feel safer if we go in groups
Seems like whenever there's trouble the police come here, and
when there isn't trouble they really keep an eye on you
There's certain places I like to go downtown, because they don't
treat you different or special
We have to join a club of people who aren't disabled, and it's
neat
Four of us are going to get a regular house by ourselves and
be able to do everything

Relationships:

We want the same things as normal people, marriage, home, family
of our own
I'm glad they're finally helping us understand about sex and
sexual feelings - it isn't scary anymore
Ever notice how many retarded people are really good at working
with little children?
I wish I could get to be friends with my mom and dad
We get along OK with each other, but we re not the best role
models for each other

Personal Power:

You've got to be on your own and responsible
I wish I were free from my mother
I cash my own checks
Making your own decisions
Control your own time
You can go to the store when you want
I like human-sized groups

APPENDIX THREE

KEEPING THE PROMISE OF THE LANIERMAN ACT;

Report of the California Assembly Office of Research

Just as People First was getting ready to put this report on paper, the California Assembly Office of Research released the first volume of a study entitled "Keeping the Promise of the Lanterman Act", in response to bi-partisan legislation sponsored by the State Council on Developmental Disabilities. The Lanterman Development Disabilities Services Act, which is Division 4.5 of the California Welfare and Institutions Code, is the legal basis for the system of services that is the subject of this report.

The Assembly Office of Research report has been reviewed wholly or in large part by every member of the task force. The review was an exciting experience, because so many of the things the task force saw and felt and tried to analyze are stated in ways in the Assembly Office of Research report that simply couldn't be said as clearly or forcefully in a less professional report, such as this one.

The Assembly Office of Research report helped the task force realize that the most complete statement of the value system which holds groups like People First together is the Lanterman Act itself. It seems that almost everybody who deals with developmental disabilities argues about what the word "normalization" means and whether or not to use it - but anyone who has been subjected to "institutionalization" knows that if normalization is the opposite of that it's a goal worth fighting for with all your

might. And the Lanterman Act is a law written by the Legislature of California that is based entirely on the principles of normalization and deinstitutionalization.

The People First task force was very conscious of those principles as it went around the state talking to clients of the developmental disabilities service system, as it observed where and how disabled people live when they are being dealt with in something other than a home-like setting, as it visited the system's vocational and educational services and talked to consumers receiving those services, and as it listened to people who were trying to make it on their own and avoiding the system as much as possible.

The net effect of the task force's work was depressing and alarming - and it is consistent with our reading of the Assembly Office of Research's report findings. Despite some very good things that are happening, and despite the hard and selfless work of some truly wonderful and caring people in the system, the reality is that there is far more evidence than not that throughout California's developmental disabilities service system, THE LAW IS BEING PERSISTENTLY IGNORED AND/OR BROKEN.

Much of this report has expressed - from the viewpoint of the people who are at the bottom of the heap, the consumers - what the Assembly Office of Research report is telling the people at the very top, the people who make the laws and the people who are supposed to implement and enforce the laws. The truth is that the best law in the world isn't worth anything if it isn't made to work in the real world. And both reports say the same thing — there's a very, very long way to go before the developmental disabilities service system dares to claim that it is keeping the promise of the Lanterman Act.



STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

November 3, 1983

Mr. Theo A. Bruinsma, Chairman
State Job Training Coordinating Council
404 South Bixel Street
Los Angeles, CA 90017

Dear Mr. Bruinsma:

The State Council on Developmental Disabilities and the California Governor's Committee for Employment of the Handicapped, at concurrent meetings of October 27 and 28, 1983, adopted the attached Resolution regarding the service to people with disabilities.

The State Council is an independent state agency with mandated responsibilities under federal and state law to plan and coordinate resources in order to insure the legal, civil, and service rights of the more than 300,000 individuals with developmental disabilities in California. Accordingly, the Council has been actively developing policies and monitoring issues related to training and employment of persons with developmental disabilities. Membership of the Council is composed of private citizens and government officials.

The Governor's Committee is a volunteer organization whose mission is to facilitate the employment of persons with disabilities. It is composed of eighty persons appointed by the Governor representing business, labor, government, education, and persons with disabilities. The committee is involved in all aspects and issues that affect the ability of persons with disabilities in obtaining employment. Some of these are attitudes, transportation, accessibility, training, and legislation. The major way the committee has successfully functioned for many years is to foster partnership between the private and public sector.

Both the State Council and the Governor's Committee have previously expressed concern regarding the lack of participation and the underserving of persons with disabilities by the Comprehensive Employment and Training Act systems.

Since the establishment of the Job Training Partnership Act, the Council and the Governor's Committee continue to be concerned by the potential underserving of people with disabilities. The State Council expressed this in its June 23, 1983 letter to you.



The State Job Training Coordinating Council encourages the State Employment Development Department and the Governor to give high priority to the funding of demonstration projects for handicapped persons which could serve as innovative programs throughout the state.

The State Job Training Coordinating Council requires the State Employment Development Department, Job Training Partnership Office, to include specific commentary regarding services to the handicapped in the evaluation of proposed program plans of the service delivery areas.

The State Job Training Coordinating Council encourages the Department of Labor to provide flexibility in program planning for the handicapped by allowing additional funding to offset the higher costs, longer training programs, and placement efforts.

2. Identify alternatives to current Supplemental Security Income issues that are both counter-productive and act as barriers in employment of persons with handicaps.
3. Encourage local Committees for Employment of the Handicapped, Department of Rehabilitation, organizations and agencies that serve the interests of persons with handicaps, and local labor organizations to monitor the implementation of the Job Training Partnership Act to ensure:
 - compliance with Section 504;
 - conformity with policies of the California Governor's Committee for Employment of the Handicapped and the State Council on Developmental Disabilities; and
 - persons with disabilities participate in the service delivery area/Private Industry Council planning process.

This statement and resolution was adopted by the Governor's Committee for Employment of the Handicapped and the State Council on Developmental Disabilities on October 28, 1983.

11/1/83
OM:nd

R E S O L U T I O N

WHEREAS, the State of California is committed to the total development of human resources for all of its citizens; and

WHEREAS, a significant number of handicapped California citizens of working age within all ethnic minorities and significant population segments are structurally unemployed and not receiving employability services of any kind; and

WHEREAS, this dependent status is demeaning to those handicapped persons who want to work and participate in our economy as tax paying citizens; and

WHEREAS, the Job Training Partnership Act of 1982 and other federal and state legislation repeatedly emphasize services to handicapped persons which would maximize the public cost-benefit of such programs by substantially reducing both medical disability and public assistance costs; and

WHEREAS, current legislation requires the coordination and linkage of all California employment and training service programs; the representation of handicapped on all Job Training Partnership Act planning bodies; the consideration of the special needs of handicapped persons in the design of programs; nondiscriminatory and affirmative action provisions on behalf of handicapped persons; and

WHEREAS, according to available statistics, California's handicapped citizens appear to have been greatly under served by Comprehensive Employment Training Act programs in relation to their incidence in the population;

NOW THEREFORE BE IT RESOLVED, that the California Governor's Committee for the Employment of the Handicapped and the State Council on Developmental Disabilities will:

1. Strongly encourage the State Job Training Coordinating Council to adopt a formal policy of support for persons with handicaps (text of policy follows) and to seek the advice and counsel of the California Governor's Committee for Employment of the Handicapped and the State Council on Developmental Disabilities.

TEXT OF POLICY TO BE ADOPTED BY STATE JOB TRAINING COORDINATING COUNCIL

The State Job Training Coordinating Council encourages the coordination and linkage of all California employment and training and human services programs to ensure the participation of persons with handicaps in the Job Training Partner-

ship Act. Such participation would maximize the public cost impact of such programs by substantially reducing both medical disabilities and public assistance cost for persons with handicaps.

The State Job Training Coordinating Council encourages the Private Industry Councils and service providers to establish an affirmative action plan for outreach, training, placement and enhancement of handicapped individuals in employment and training programs under the Act; and to contribute to the maximum extent feasible to the elimination of artificial barriers to the employment and occupational advancement of handicapped persons.

The State Job Training Coordinating Council encourages the Private Industry Councils to develop programs with the flexibility to accommodate the special needs of handicapped persons, some of whom will require longer training periods and placement periods at a higher cost per participant than those for nonhandicapped participants, and to evaluate these programs with flexibility.

The State Job Training Coordinating Council encourages the Private Industry Councils and other employment and training service providers to recognize the special needs of handicapped persons in their jurisdictions and develop programs that are specifically designed to meet the needs of persons who cannot be effectively served in the mainstream of employment and training programs.

The State Job Training Coordinating Council encourages the Private Industry Councils and other employment and training providers to ensure handicapped representation on their advisory councils.

The State Job Training Coordinating Council encourages the Private Industry Councils to cooperate with local field offices or state departments, local communities, education, private nonprofit and profit organizations that serve persons with handicaps in the screening and identification of handicapped persons who would be eligible to participate in the Job Training Partnership Act programs and to coordinate resources and services to meet the needs of handicapped participants.

The State Job Training Coordinating Council encourages the Private Industry Councils to implement staff in-service and community training sessions in disability awareness on a broad basis in cooperation with state agencies, community-based rehabilitation facilities, and consumer advocacy groups for the disabled.

§416.1180

(2) If you leave the State for more than 90 calendar days, you are no longer living there.

RULES FOR HELPING BLIND AND DISABLED INDIVIDUALS ACHIEVE SELF-SUPPORT

§ 116.1180 General.

One of the objectives of the SSI Program is to help blind or disabled persons become self-supporting. If you are blind or disabled, we will pay you SSI benefits and will not count the part of your income that you use of set aside to use under a plan to become self-supporting. (See ii 416 1112(c)(6) and 1124(0)(11).) You may develop a plan for achieving self-support on your own or with our help. As appropriate, we will refer you to a State rehabilitation agency or agency for the blind for additional assistance in developing a plan.

§ 116.1181 What a plan to achieve self-Support is.

A plan to achieve self-support must—

- (a) Be designed especially for you;
- (b) Be In writing;
- (c) Be approved by us (a change of plan must also be approved);
- (d) Be designed for an initial period of not more than 18 months. We may extend the period for up to another 18 months if you cannot complete the plan in the first period. We may allow a total of up to 48 months to fulfill a plan for a lengthy education or training program;
- (e) Show your specific occupational goal;
- (f) Show what money you have and will receive, how you will spend it, and how you will use it to attain your occupational goal; and
- (g) Show how the money you set aside under the plan will be separated from your other funds.

• 116.1182 When we begin to count the income excluded under the plan

We will begin to count the earned and unearned income that would have been excluded under your plan in the quarter in which any of the following circumstances first exist:

Title 20--Employee Benefits

- (a) You fall to follow the conditions of your plan;
- (b) You abandon your plan;
- (c) You complete the time schedule outlined in the plan; or
- (d) You reach your goal as outlined in the plan.

APPENDIX—LIST OF TYPES OF INCOME EXCLUDED UNDER THE SSI PROGRAM AS PROVIDED BY FEDERAL LAWS OTHER THAN THE SOCIAL SECURITY ACT

Many Federal statutes in addition to the Social Security Act provide assistance or benefits for Individuals and specify that the assistance or benefit will not be considered in deciding eligibility for SSI. We have listed these statutes in this appendix and have placed them in categories according to the kind of income or assistance they provide. The list gives the name of the Federal statute (where possible), the public law number, and the citation. Each item briefly describes what the statute provides that will not reduce or eliminate an SSI payment. More detailed information is available from a social security office or by reference to the statutes.

We update this list periodically. However, when new Federal statutes of this kind are enacted, or existing statutes are changed, we apply the law currently in effect, even before this appendix is updated.

I. Food

- (a) Value of food coupons under the Food Stamp Act of 1911, section 1301 of Pub. L. No. 95-113 (91 Stat. 968.1 U.S.C. 2011(b)).
- (b) Value of federally donated foods distributed under section 32 of Pub. L. No. 74-320 (49 Stat. 774) or section 416 of the Agriculture Act of 1949 (63 Stat. 1058. 1 CFR 250.6(e)(9)).
- (c) Value of free or reduced price food for women and children under the—
 - <1> Child Nutrition Act of 1966, section 1K(b) of Pub. L. No. 89-642 (80 Stat 889. 42 U.S.C. 1780(b)) and section 11 of that Act as added by Pub. L. No. 92-433 (86 Stat. 729.42 U.S.C. 1786); and
 - (2) National School Lunch Act, section 13(h)(3), as amended by section 3 of Pub. L. No. 90-302 (62 Stat. 119. 42 U.S.C. 1761(h)(3)).

II. Housing and Utilities

- (a) Assistance to prevent fuel cut-offs and to promote energy efficiency under the Emergency Energy Conservation Services Program or the Energy Crisis Assistance Program as authorized by section 222(aX5) of the Economic Opportunity Act of 1964, as amended by section 5(d)(1) of Pub. L. No. 93-644 and section 5(a)(2) of Pub. L. No. 95-

Chapter III—Social Security Administration

568 (88 Stat. 2294 as amended. 42 U.S.C. 2809(a)(5)).

(b) Fuel assistance payments and allowances under the Home Energy Assistance Act of 1980, section 313(c)(1) of Pub. L. 96-223 (94 Stat. 299. 42 U.S.C. 8612(c)(1)).

(c) Value of any assistance paid with respect to a dwelling unit under—

(1) The United States Housing Act of 1937:

- (2) The National Housing Act;
- (3) Section 101 of the Housing and Urban Development Act of 1965; or
- (4) Title V of the Housing Act of 1949.

(d) Payments for relocating, made to persons displaced by Federal or federally assisted programs which acquire real property, under section 216 of Pub. L. No. 91-646, the Uniform Relocation Assistance and Real Property Acquisition Policies Act of 1910 (84 Stat. 1902. 42 U.S.C. 4636).

III. Education and Employment

(a) Incentive allowances for individuals under section 124(a)(3) of the Comprehensive Employment and Training Act (CETA) (92 Stat 1943. 29 U.S.C. 826(a)), also earnings and allowances paid to a youth in certain training or employment programs (applies to the youth and the youth's family) under section 446 of CETA (92 Stat. 1992. 29 U.S.C. 921).

(b) Grants or loans to undergraduate students made or Insured under programs administered by the Secretary of Education under section 501 of the Higher Education Amendments of 1968, Pub. L. No. 90-515 (82 Stat. 1063).

(c) Any wages, allowances, or reimbursement for transportation and attendant care costs, unless excepted on a case-by-case basis, when received by an eligible handicapped individual employed in a project under title VI of the Rehabilitation Act of 1913 as added by title II of Pub. L. No. 95-602 (92 Stat. 2992. 29 U.S.C. 195(bXc)).

IV. Native Americans

(a) Revenues from the Alaska Native Fund paid under section 21(a) or the Alaska Native Claims Settlement Act, Pub. L. No. 92-203 (85 Stat. 713. 43 U.S.C. 1620(a)).

(b) Indian tribes-distribution of per capita Judgment funds to members of—

(1) The Blackfeet and Gros Ventre Tribes under section 4 of Pub. L. 92-254 (86 Stat.. 65.25 U.S.C. 1264);

(2) The Grand River Band of Ottawa Indians in Indian Claims Commission docket numbered 40-K under section 6 of Pub. L. No. 94-540 (90 Stat. 2504);

(3) Tribes or groups under section 7 of Pub. L. No. 93-134 (87 Stat. 468. 25 U.S.C. HOT); and

(4) The Yakima Indian Nation or the Apache Tribe of the Mescalero Reservation

§416.1201

as authorized by section 2 of Pub. L. No. 95 433 (92 Stat. 1047. 25 U.S.C. 609c 1).

(c) Receipts from land held in trust by the Federal government and distributed to members of certain Indian tribes under section 6 Of Pub. L. No. 94-114 (89 Stat. 579).

V. Other

(a) Compensation provided volunteers in the foster grandparents program and other similar programs under sections 404(g) and 418 of the Domestic Volunteer Service Act of 1973 (87 Stat. 409. 413. 42 U.S.C. 5044(g) and 5058).

(b) Any assistance to an individual (other than wages or salaries) under (he Older Americans Act of 1965, as amended by section 102(h)(1) of Pub. L. No. 95-478 (92 Stat. 1515. 42 U.S.C. 3020a).

Subpart I—Resources and Exclusions

AUTHORITY: Secs. 1102, 1601, 1602, 1611, 1612, 1613, 1614(f), and 1631(d), 49 Stat. 647 as amended, 86 Stat 1465, 1466, 1468, 1470, 1413; 42 U.S.C. 1302, 1381, 1381a, 1382, 1382a, 1382b, 1382c(f), and 1383(d), unless otherwise noted.

SOURCE: 40 FR 48915, Oct. 20, 1975, unless otherwise noted.

§416.1201 Resources; general.

(a) Resources; defined. For purposes of this Subpart L, resources mean cash or other liquid assets or any real or personal property that an individual (or spouse, if any) owns and could convert to cash to be used for his support and maintenance. If the individual has the right, authority or power to liquidate the property, or his share of the property, it is considered a resource. If a property right cannot be liquidated, the property will not be considered a resource of the individual (or spouse)

(b) Liquid resources; defined. Liquid resources are those assets that are in cash or are financial instruments which are convertible to cash. Liquid resources include cash on hand, cash in savings accounts or checking accounts, stocks, bonds, mutual fund shares, promissory notes, mortgages, and similar properties. Liquid resources, other than cash, are evaluated according to their equity value.

(c) Non-liquid resources; defined. (1) Non-liquid resources include all other properties, the term includes both real and personal property. Non-liquid re-

SI 00870.000 Plans for Achieving Self-Support for Blind or Disabled

Section

Requirements for Exclusion

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Ad as amended in 1972-See. 1612(b)(4)(A) and (B). 1613(a)(4) Social Security Amendments of 1972-Sec. 301 Regulations No. 16 Subpart K, Section 416.1180-416.1182. Subpart L. Section 416.1226

Requirements for Exclusion

00870.001 General

One objective of the Supplemental Security Income (SSI) program is to provide needy disabled or blind individuals under age 65 with the opportunity to attain or regain the ability to become self-supporting. These disabled or blind individuals are referred to the State VR or agency for the blind for appropriate evaluation, rehabilitative, and counseling services (DI 00502.001). The administration encourages use of these services and similar programs focusing on specific disabling conditions, e.g., cerebral palsy. However, some individuals are concerned that use of these services and related training

could result in loss of SSI payments and related benefits, such as Medicaid, due to excess income/resources. To relieve this concern the law provides for establishment of a plan for achieving self-support (PASS).

always applied after all other such exclusions (with the exception of IRWE (see CM A6403ff)), that allows an individual to become eligible for SSI while receiving and accumulating some otherwise nonexcludable income/resources. In order to qualify for

entering or returning to employment and be willing to participate in SSA approved training to achieve the occupational objective.

Under a PASS, a disabled or blind individual is permitted to receive earned and unearned income, and accumulate resources over a reasonable period of time in order to obtain occupational training and education, purchase occupational equipment, establish a business, etc., thereby encouraging him or her to become financially self-supporting.

The legislative history of the 1972 Amendments to the Social Security Act indicates that the provision for PASS'S should be liberally construed if necessary to accomplish the self-support objective. However, this does not imply that if the individual has an approved PASS, all income and resources are automatically excluded. Rather, it permits the exclusion of that part of the income and resources specifically identified as being necessary to fulfill a plan. The criteria governing establishment of an approvable PASS provides defined limits on when and for what purposes income and resources can be excluded.

The exclusion of income under a PASS is applicable only for determining current eligibility/payment amount under SSI; i.e., helping the individual meet SSI income and resource limits. It has no effect on the calculation of earned income used to determine whether a disabled individual is engaging in sub-

stantial gainful activity (SGA) or qualifies for a trial work period (TWP) (DI 00503.001).

Recent legislation permits extension of a TWP for 15 months beyond the original 9 months evaluation (DI 00504.180). If an individual is engaged in a PASS prior to the beginning of the extended TWP, the plan continues in effect during the extended period. Standard diary, evaluation, and documentation procedures should be followed. No new plans should be developed during this period of special payments. However, plan extensions and revisions can be developed during this period using the criteria in SI 00870.070. The new legislative provisions also allow extension of payments in certain situations beyond medical cessation of disability or after the level of SGA has been attained (DI 00502.043, 00504.180). In these situations previously established plans continue in effect, but no new plans should be initiated. Plan extensions and revisions can also be developed in these situations using the SI 00870.070 criteria.

Before applying the PASS exclusion, consider all (0150.000). If countable income or excess resources remain after applying all other exclusions, consider the possibility of further income/ resources exclusions through the development of a plan for achieving self-support.

Income exclusions of higher priority include but are not limited to State supplied assistance based on need, tuition and fee portions of grants, scholarships, fellowships, and work expense for the blind. Money/services received from VR by an individual participating in a program are also excluded prior to consideration of a plan. Use the same procedures in applying the resource exclusions, utilizing the guidelines in SI 01110.000. When deeming of income and resources from a parent, ineligible spouse, or eligible spouse is applicable, keep in mind that deemed income and resources may be excludable under a PASS as is support and maintenance in kind, see SI 00850.000 and SI 01110.000.

The exclusion of the work expenses of the blind permits excluding from countable income the income used to meet expenses reasonably attributable to the earning of any income by the blind individual. A PASS would be used if the individual has excess resources not taken care of by the resources exclusions of higher priority. To qualify for this exclusion, an individual must meet the medical criteria for statutory blindness. Those individuals who do not meet the criteria and are determined disabled with a visual impairment do not receive this exclusion.

Recent legislation added an additional exclusion for earned income, Impairment Related Work Expenses (IRWE). This provision permits the deduction from earnings of an amount equal to the cost (to the individual) of such items/services as attendant care, medical devices, prosthesis, reading aids for the blind, etc., which are necessary to engage in employment regardless of whether these items and services

are also needed for non-work activities. This exclusion applies only to the costs paid by the individual from earned income. The IRWE exclusion cannot be applied until initial eligibility for SSI payments is established. Should SGA become an issue after an individual becomes eligible for SSI payments, the IRWE exclusion can be applied to reduce the income below the level of SGA (CM A6403 ff).

The PASS exclusion can be used to reduce excess income and resources which frequently are impediments to SSI eligibility and payments. Under the PASS exclusion the item or expense incurred must relate directly to fulfillment of the individual's occupational objective; i.e., not otherwise needed for daily activity. The source of the payment/savings for the expenses or items is immaterial. The exclusion of income under a PASS does not affect calculation of earned income to be used in determining if an individual is engaging in SGA (DI 00503.001 ff).

Exclusions under IRWE and PASS are mutually exclusive. An item excluded as an IRWE cannot be excluded under a PASS.

If both an individual and a spouse are disabled or blind, each may have a plan. Develop a separate PASS for each member of the couple.

00870.010 Exclusion Criteria for a Plan for Achieving Self-Support

For income/resources to be excluded as necessary to fulfill a PASS the following conditions must be met (see SI 00870.040 for the application of these criteria):

- A. A specific plan for the individual must exist in writing.
- B. The plan must contain:
 1. A designated occupational objective;
 2. Specific savings/planned disbursement goals directly related to the objective;
 3. A list of objective related items or activities requiring savings or payments and the anticipated amounts; and
 4. A specific period of time for achieving the objective.
- C. The plan must identify and segregate any money or other resources being accumulated and conserved toward the accomplishment of the occupational objective.
- D. The plan must be current: i.e., the time period covered by the plan must not have expired. (A plan cannot be established earlier than the date of application for SSI or the first point of documented interest in a plan).
- E. The plan must be approved by SSA.
- F. The individual must be performing currently in accordance with the provisions of the approved plan for achieving self-support in order to receive the advantages accruing from the continuing income/resource exclusions under the plan.

00870.020 When a Plan for Achieving Self-Support Should Be Considered

Conceptually, every disabled and blind SSI applicant/recipient may, at some point, use a PASS. However, the most likely candidates for a plan are those individuals who are:

- A. Clients of a State vocational rehabilitation agency or a State agency for the blind (Hereafter, VR will denote both of these agencies);
- B. In school or in a training program;
- C. Marginally employed (including self-employment) or interested in obtaining employment or establishing a business;
- D. Inquiring about rehabilitation;
- E. Veterans Administration (VA) clients;
- F. Working with private disability adjustment services, e.g., United Cerebral Palsy;
- G. Alleging they wish to have a plan to become self-supporting.

If any of the above indicators are present, discuss with the individual, at the time of initial application, at redetermination, or when notification of potential referral for vocational rehabilitation is given (DI 00502.011), the effect that an approved PASS may have upon his or her eligibility/payment amount.

A PASS should also be considered before a disabled or blind individual's application is denied on the basis of excess income or resources. Consideration should also be given to development of a plan when the individual could be suspended for excess income/excess resources. It may not be necessary to discuss development of a PASS in great detail with every claimant in the above categories, but there should be some discussion about each individual's employment/training in order to determine whether consideration of a PASS is appropriate. Document the discussion and the individual's decision to pursue or not to pursue a PASS on a Report of Contact (RC)(SSA-5002).

Example:

During an SSI disability application interview the claims representative (CR) learned that the claimant, Mr. Michael Stone, may have income in excess of SSI limits. Mr. Stone operates a small stand in an office building selling pens, pencils, and stationary, and the income fluctuates based on his sales and inventory requirements. Mr. Stone says he applied for SSI because he is just getting started and is not able to rely on a regular income from his business. He also indicated that if he could expand his stock and variety of items his business income could increase. Without some assistance, such as SSI, he does not have enough money for daily needs plus the added stock. He feels his expanded business would end his need for SSI by showing a profit after one year.

Since Mr. Stone might not be eligible for SSI without a PASS and he is interested in becoming self-supporting, the CR should discuss the possibility of a PASS with him. If he agrees to a PASS, use

the criteria in SI 00870.040 to help him prepare his plan.

00870.030 Development of a Plan for Achieving Self-support

A. Who May Develop a PASS

There is no restriction on who may develop a PASS for a disabled or blind individual. However, they are often developed by:

1. A VR agency;
2. The Veterans Administration;
3. Any public or private social service agency;
4. A sheltered workshop;
5. Any employer;
6. SSA;
7. Anyone assisting the individual; or
8. The individual.

The evaluation of self-support plans is the responsibility of SSA. Because of the experience VR agencies, the VA, and other public or private agencies have in developing individual rehabilitative programs, SSA requests their assistance when the feasibility of an occupational objective is not certain because of the nature of the individual's disability. SSA also can look to these groups for assistance in planning the schedule of activity to achieve the plan objective. Each district office (DO) should develop an Information Exchange Form to use in requesting information from the appropriate agency or group (SI 00870.100, Exhibits 2,3). After this information is compiled, the SSA representative, CR or above, will evaluate the plan for compliance with the criteria discussed in SI 00870.040, apply the income and resource exclusions, and prepare a written determination of approval or disapproval (SSA-553).

B. Formulation of a PASS

1. WHEN A PASS IS NECESSARY TO ESTABLISH OR RETAIN ELIGIBILITY

Where the establishment of a PASS appears feasible and the individual would be ineligible without it:

- a. Discuss the effect that a PASS might have on the individual's SSI eligibility/payment amount. If the establishment of a PASS appears practical, and the income and resource requirements would not be met without a plan, delay final system input and begin PASS development, establishing a 30 day follow-up diary. (This development should be done concurrent with other non-medical development for the case).
- b. Refer the claimant to the appropriate agency for rehabilitation services (DI 00502.001 ff) and, if needed, assistance in defining the occupational objective and the training, schooling, and equipment necessary to achieve the objective.

- c. If the agency is helping with development of the plan, send a copy of a DO Information Exchange Form (SI 00870.100, Exhibits 2,3) for the agency to record the information and return it to the DO.
- d. Advise the individual to contact the DO as soon as the information for the PASS has been obtained, or if the individual decides not to develop a PASS because eligibility for SSI payments is affected by his or her action.
- e. If the DO hears nothing from the individual or agency within the 30 days after referral, contact the individual /agency by telephone to determine if plan development is being pursued. If there is interest in a plan, record the information regarding the necessary elements of a plan and determine if this information is sufficient to establish a plan, allowing for revision after establishment of initial eligibility. Prepare a written determination on the plan, including a reference to the anticipated revision. Failure to begin development of plan elements by this point indicates questionable interest. If the claimant is indefinite about developing a PASS, explain the result of not pursuing the plan, i.e., not becoming eligible for SSI or loss of SSI eligibility. Consider failure to develop at least the basic elements of a plan a decision not to pursue a plan. In this situation, or when an individual says he or she is not longer interested in a plan, document the file with an RC indicating the individual's decision and date of contact. Complete final system input.

Example:

During a recipient initiated redetermination interview, it is revealed that Jack Thomas, a paraplegic, now has enough income and resources to preclude further SSI payments. Mr. Thomas alleges that he is participating in a VR funded on-the-job training program in a sheltered workshop. He is training to become a self-employed welder. VR currently is arranging for special van transportation. It is further learned that this program is to last for a period of 18 months, at the end of which Mr. Thomas is expected to obtain employment outside of the sheltered workshop. At that time, he must also supply his own transportation and equipment. Mr. Thomas is expected to obtain specially equipped van for this purpose. In order to purchase this van, he will need his SSI payments to supplement his resources to make a down payment on the van and the equipment at the end of the on-the-job training program.

The CR helped the individual write out the details on his plans for achieving his occupational objective

and contacted VR to confirm the approximate dates for the program. The CR explained the PASS requirements, including the need for a separate account, to the individual. After opening the separate account, Mr. Thomas returned to the DO with proof of the account (i.e., bank book and account number), reviewed the PASS prepared by the CR, and agreed to function in the PASS as described. The CR prepared the determination on the PASS, adjusted Mr. Thomas' excluded income and resources, and made the necessary adjustments for continued SSI payments.

2. WHEN A PASS IS NOT NECESSARY TO ESTABLISH OR RETAIN ELIGIBILITY

When it appears an individual could benefit from a PASS, but it is not necessary to establish or retain the individual's SSI eligibility, and the individual has no plan but indicates an interest in pursuing one:

- a. Adjudicate the claim to pay or input the redetermination without any PASS exclusions;
- b. Prepare an RC for the claimant's file describing his or her desire to establish a PASS and his or her thoughts about an occupational objective;
- c. Refer the claimant to the appropriate agency for rehabilitation services (DI 00502.001 ff) including a copy of the above mentioned RC along with any appropriate referral documents;
- d. If the agency is helping with the development of the plan, send a copy of the DO Information Exchange Form (SI 00870.100. Exhibits 2,3) for the agency to record the information and return the form to the DO;
- e. Diary the case for a follow-up 90 days after referral;
- f. Advise the individual to contact the DO as soon as the information for the PASS has been obtained or if the individual decides not to develop a plan;
- g. If the DO hears nothing from the individual or agency within the 90 days after referral, contact the individual/agency by telephone to determine if plan development is being pursued. If there is interest in a plan, record the information regarding the necessary elements of a plan and determine if this information is sufficient to establish a plan. Prepare a written determination on the plan. Failure to begin development of plan elements by this point indicates questionable interest. Consider failure to develop at least the basic elements of a plan a decision not to pursue a plan. In this situation or when an individual says he or she is no longer interested in a plan, document the file with a Report of Contact indicating the individual's decision and date of contact.

Establishment of a Plan for Achieving Self-Support

00870.040 Application of Criteria for a Plan for Achieving Self-Support

A. Procedures for Determination

DO personnel, CR's and above, are responsible for development of a PASS, i.e., assessing the individual's interest in a plan, helping the individual develop the various elements necessary to attain the plan's objective (including referral to the appropriate agency for help), identifying income and resources appropriate for exclusion, and preparing a written determination of the plan's acceptability. (Claims Representative Trainees (CRT) are permitted to prepare PASS'S and determinations, but these must be reviewed and signed by a CR before taking effect).

B. Necessary Elements

A PASS must be a specific plan devised for the individual (or by the individual) to enable him or her to attain a specific occupational objective and, thus, become self-supporting. To be approved for SSI purposes, each PASS must meet the following requirements.

1. MUST BE IN WRITING

Each individual must have a plan specifically written for him or her. This plan need not be written according to a predetermined format. However, the plan must contain all of the elements necessary to make a decision to approve or disapprove the PASS, as listed in this section. When the individual is receiving VR or VA rehabilitation services, he or she should be able to obtain a copy of the rehabilitation plan from VR or VA case records to help in preparing the plan. The essential elements may also be obtained from the individual by recording them on an SSA-795, signed by the individual. Once all of the essential elements have been obtained and recorded on the SSA-795 or a DO Information Exchange Form (SI 00870.100. Exhibits 2,3), the DO should prepare a written special determination (SSA-553) to approve or disapprove the PASS (SI 00870.100. see exhibit 1). A double signature is not required unless the determination is prepared by a CRT.

2. MUST HAVE A DESIGNED AND FEASIBLE OCCUPATIONAL OBJECTIVE

- a. Identification of a Designated and Feasible Occupational Objective

A designated and feasible occupational objective is one which:

- 1) Identifies the individual's proposed occupation, e.g., computer programmer.
- 2) Can be attained, given the individual's impairment, and

- 3) Will produce earned income sufficient to eliminate, or at least reduce SSI payments within a reasonable period of time.

NOTE: Working toward accomplishment of a non-occupational goal, such as attaining or improving self-sufficiency (i.e., basic living skills) or homemaking capability, does not qualify as an acceptable occupational objective for a PASS.

If an individual has achieved the ability for self-support, income and resources cannot be excluded under a PASS; e.g., further specialized or advanced education or training is being sought for the purpose of improving potential earning capability. Not only would a PASS be inappropriate under such circumstances, but, in the case of the disabled, as distinguished from the blind, the question of continuing disability would also need to be resolved.

This is not to say, however, that in no case would specialized or advanced training be an appropriate basis for a PASS. A severely disabled individual may have a well paying job but because of special needs he or she may not be self-supporting.

An individual is considered self-supporting if the individual's income is, after application of all other SSI exclusions, sufficient to meet the costs of the individual's disability/blindness related expenses and still make him or her ineligible for SSI payments.

Example:

Bess Turner, a blind teacher, wants to stop teaching while she takes additional courses to earn a master's degree to permit her to go into an administrative position rather than continue teaching. She plans to finance this additional education from a monthly allowance to be paid by her brothers and from her \$3,000 savings. This planned disbursement of her income and resources cannot be excluded under a plan for achieving self-support. The additional degree is not required to maintain her present teaching position but is primarily for improving her already demonstrated earnings capacity. In other words, she has already achieved and demonstrated an ability to be self-supporting. It is not the purpose of a plan for achieving self-support to assist a self-supporting individual to achieve his or her optimum level of earnings.

b. VR Evaluation: Presumed Occupational Objective

During the period that a VR agency is performing a diagnostic study/evaluating the individual to determine the appropriate rehabilitation services to offer, it can be presumed that a designated and feasible occupational objective exists. Thus, if an individual will be going through this process or is presently involved in it, a PASS may be developed provided there are evaluation related expenses that meet the criteria for exclusion of income/resources under a PASS. Rehabilitation evaluation related expenses could include transportation, meals, maintenance of second residence temporarily, etc.

In this situation, a PASS may be developed with an occupational objective of "VR Evaluation," but

it must meet all other requirements set forth in this section. At the end of the evaluation period, the individual's PASS must be revised to include a new occupational objective that will meet the criteria in a. above. This evaluation time does count toward the maximum length of a PASS. Changes in planned savings/disbursements, as well as in other exclusions, are to be expected at this point. When this occurs, follow SI 00870.070.

If the VR agency is unable to determine a viable occupational objective for the individual, the PASS will be terminated at the end of the evaluation period. The case must then be redetermined in accordance with SI 02305.005.

Example:

During his application interview, Ben Jones, a title II recipient, told the CR he was participating in a VR evaluation program to determine an appropriate rehabilitation goal for him. Ben is a paraplegic, with traumatic onset. Because of his title II benefits it appears Ben will not be eligible for SSI. Since a PASS appeared feasible because of the impact on his eligibility and his interest in returning to employment, the provisions for a plan were explained to Ben. He indicated an interest in developing a plan.

VR was contacted for information on the evaluation program. The CR reviewed the information and prepared a determination for an approved plan with an occupational objective of "Rehabilitation Evaluation" and an achievement period of 3 months. Since Ben had to live away from home for part of the evaluation period, the cost of this second residence was excluded as a necessary expense as was the cost of daily transportation.

At the end of the VR evaluation period, Ben requested a revised plan with an occupational objective of machinist. Utilizing the VR evaluation report and training outline, the CR will prepare a revised plan and determination to approve or disapprove the plan.

3. MUST HAVE SPECIFIC SAVINGS/PLANNED DISBURSEMENT GOALS RELATED TO ATTAINMENT OF THE OCCUPATIONAL OBJECTIVE

Development of specific savings/planned disbursement goals requires a careful assessment of the steps necessary for the individual to reach the occupational objective. This process is important because any income and resources to be excluded under a PASS must be related to attainment of an occupational objective. Only those goods and services specifically required to achieve the occupational objective can be excluded under a PASS. Disbursements/savings for goods and services that an individual requires with or without an occupational goal cannot be excluded under a PASS, e.g., home wheelchair ramp. The majority of expenses suggested in rehabilitation information submitted by VR, VA, etc., are appropriate. However, since many rehabilitation plans go beyond strictly occupational concerns, to include personal and social adjustment, the

expenses suggested for exclusion should be reviewed for consistency with our PASS exclusion criteria. If a question still exists regarding a proposed excludable expense, contact the agency representative by telephone for clarification.

a. Sources of Income and Resources

The source of any income and resources to be excluded under a PASS is immaterial. However, when applying exclusions of higher priority (SI 00810.010, 00840.001, 01150.001, CM A6403.4), the source of any monies is very important because these exclusions are to be applied in priority order.

Example 1:

According to the provisions of his PASS, John Williams, a disabled individual, will attend night school for 2 years in an effort to reach his occupational objective of becoming a consumer credit analyst at a commercial bank. VR will be paying for the majority of his tuition and school expenses. For additional training, John will be working part-time as a loan clerk while he is attending school. The income he receives from this training will be used to pay for the remainder of his tuition and school expenses as well as for some of his basic living needs.

In this case, the monies received from VR should be excluded under SI 00810.030.A.1. The amount of John's income used to pay tuition and school expenses is excludable under an approved plan. However, the remainder of his income is countable because he uses it for purposes not directly related to pursuit of his occupational objective.

Example 2:

According to her PASS, Laura Harris, a paraplegic, wants to become a parole officer. Toward this goal, she plans to obtain her bachelor's degree in criminology over a 4-year period during which she will have to live on campus in lieu of living at home with her parents. VR will be paying for her tuition, and Laura's church will be providing her with a flat grant of \$100 per semester. Additionally, Laura plans to work part-time in her school's financial-aid office, using this income toward her room and board expenses at school.

In this case, the VR funds for tuition are excludable under SI 00810.030.A 1. The \$100 flat grant from Laura's church along with her own income may be excluded under a PASS, provided that she identifies the money's use, which must be directly related to attainment of her occupational objective. (Expenses for the room and board she requires while attending school are excludable because they are directly related to her occupational objective which requires that she lives away from home).

b. Savings and Disbursements

Savings and disbursement designations that are part of a PASS may be for many different goods and services provided these goods and services are di-

rectly related to achieving the occupational objective. Some of the frequent savings designations are:

- 1) Savings toward the purchase of equipment necessary to carry on a trade or business;
- 2) Savings toward the payment for educational or vocational training necessary to attain an occupational goal; and
- 3) Savings toward purchase of items associated with this educational or vocational training (e.g., support and maintenance at school, books, special equipment, transportation, etc.).

Some of the frequent disbursements are:

- 1) Payment for transportation to employment/training;
 - 2) Purchase of meals at the place of employment/training; and
 - 3) Purchase of required uniforms.
4. MUST PROVIDE FOR THE IDENTIFICATION AND SEGREGATION OF ANY MONIES AND OTHER RESOURCES BEING ACCUMULATED

Liquid resources (money, bonds, stock, etc.) to be excluded under a PASS must not be commingled with other resources since identification of the designated resources is necessary when evaluating compliance with plan provisions. If the individual is currently commingling other resources with the resources to be used for fulfilling a PASS: e.g., only one bank account for all funds, explain that in order for such resources to be excluded, they must be kept in a separate account. Interest earned on the PASS savings should be applied toward the monetary goal. The individual must then supply proof, such as a savings account passbook, with account number, showing the amount of funds which has been segregated from any other resources for the PASS.

Example:

Sandy Morton, a disabled recipient, reported to the DO that he had just been awarded a schedule of monthly compensation payments based on his disability. Being familiar with the case, the CR was aware that in performing the redetermination these payments could make Sandy ineligible due to excess income. The CR decided to discuss the potential of a PASS with Sandy, who indicated he was interested in becoming a jewelry repairman and would be interested in developing a PASS. He indicated the larger part of the money in his savings account was being saved for books and tools. The CR helped Sandy write up his plan and informed Sandy that as soon as he opened a separate account for his PASS savings and brought in proof of the account; i.e., the passbook, the PASS could be approved. The CR explained that a delay in implementing the plan could result in a loss of SSI payments. Sandy brought in the passbook two days later and the CR recorded the account number and bank name in the Pass and completed the redetermination.

S. MUST HAVE A SPECIFIC AND REASONABLE PERIOD OF TIME WITHIN WHICH THE PASS WILL BE FULFILLED

a. Duration Requirements

An approved PASS is limited to an initial period of no longer than 18 months' duration (SI 00870.080). An additional period of up to 18 months may be granted where it is determined that such an extension is required to attain the occupational goal of the previously approved PASS. When the original plan includes an occupational objective which requires extensive education or vocational training (e.g., undergraduate degree), a second extension of up to an additional 12 months may be granted.

Because a plan is designed to meet the individual's needs for achieving the occupational objective, the way SSA monitors and evaluates the individual's progress should demonstrate some flexibility. As long as the general duration guidelines are observed and the individual's circumstances and progress toward the objective justifies the additional time, extensions for specific periods of 3, 6, 12 or any number of months, but not exceeding 18 months may be granted. Each extension should be diared for the month prior to expiration of the extension to assess progress toward achievement of the occupational objective. If it is known an occupational objective will take more than 18 months to achieve, the entire program should be outlined. However, the determination of approval must address only the first 18 months. If sufficient progress is made toward the objective in those months, a second determination should be prepared for the additional time, up to 18 months. If the individual remains in compliance and the 12 month extension is appropriate, a determination should be prepared for this period.

While a plan is in effect, it may become apparent that modifications in objective, major savings goals, or substantial expenditures are necessary. When the DO becomes aware of these matters, the CR should pull the DO PASS file for the individual and, with the individual's assistance, prepare a revised plan and determination. Minor changes in expenditures or savings amounts can be recorded on an RC and attached to the file copy of the PASS. No determination is needed for minor changes. Minor changes are those that do not affect the claimant's eligibility, payment amount, or plan duration.

In some situations, due to the changes in the individual's condition or simply the plan proving not feasible for the individual, the plan should terminate and be replaced by a new plan. A new plan should be developed only where the new objective totally differs from the first objective and there is reason to believe the plan will prove successful. The DO file on the PASS should include a special determination regarding the establishment of the new plan, including reasons for its development. There is a 36 month maximum duration for the new plan that does not include extensive educational/vocational training; e.g., undergraduate degree. New plans including

such a training requirement have a 48 month maximum duration. If there are any questions concerning the feasibility of an extension, contact a collateral source such as VR for assistance.

The effective month for PASS exclusion(s) is the first month it can be established the individual is performing in accordance with the approved plan, but no earlier than the month in which an SSI application was filed.

b. Diaring Cases

- 1) When a pass is approved, establish a diary to mature in the month preceding the month in which the PASS is fulfilled (SI 00870.080) or in the 17th month after the plan is established, whichever is earlier.

When the diary matures, follow c.1) below.

- 2) If an 18-month extension is warranted and allowed, establish a diary to mature in the month preceding the month in which the PASS will be fulfilled (SI 00870.080) or in the 17th month after the month the extension is granted, whichever is earlier.

When this diary matures, follow c.2) below.

- 3) If a second extension, which must be for educational purposes, is allowed, establish a diary to mature in the month preceding the month in which the PASS will be fulfilled (SI 00870.080) or in the 11th month after the second extension is granted, whichever is earlier.

When the diary matures, follow c.3) below.

c. Expiration of Diaries

- 1) When the first diary matures, carefully assess the specific situation to determine whether the PASS has been fulfilled (SI 00870.080) or whether there is a basis for granting an additional exclusion period of up to 18 months.

If the PASS has been fulfilled or is to be terminated due to noncompliance. (SI 00870.080). process a redetermination per SI 02305.050 ff. Income excluded in accordance with a PASS will become countable the month following the month the PASS is fulfilled or terminated. Resources excluded in accordance with a PASS will become countable with the quarter following the quarter in which the PASS is terminated.

Example 1:

Alice Hughes' original PASS was established for 16 months. During the 15th month, Alice submitted a revised plan requesting an additional 5 months to attain her occupational objective. She indicated the extension was needed to complete a semester of oc-

cupationally related courses missed due to illness. Since the illness was documented by her physician and Alice was otherwise adhering to the provisions of the PASS, the CR granted the extension. A diary was established to mature in the 20th month to assess Alice's progress and potential need for additional time.

Example 2:

Bob Rettmon had a PASS with a 14 month duration. In the 13th month the DO representative evaluated Bob's progress toward his occupational objective. At this time Bob submitted a revised plan extending his PASS duration by 6 months. Bob indicated he needed the extension to accumulate additional savings to purchase the equipment necessary to achieve his occupational objective. Bob alleged the additional funds were necessary because inflation had increased the cost of the equipment as well as reduced his capacity to accumulate funds. A VR counselor confirmed Bob's allegation about the cost of the equipment. The 6 month extension was granted and a diary was established that was set to mature in the 19th month after the PASS became effective.

- 2) When the second diary matures, carefully assess the specific situation to determine whether the PASS has been fulfilled or whether there is a basis for granting an additional extension of up to 12 months. The 12 month extension can be authorized only when the PASS includes an educational or vocational training requirement which extends beyond the initial and first extension period.

If a second extension of the PASS is warranted for the individual, rediary the case as instructed in b.3) above. This final extension should have been projected in the original PASS. If the extension was not anticipated in the original PASS, the individual must provide rationale for the request. This information should then be evaluated, using a collateral source such as VR if it is appropriate. The decision on the request should be documented in the file.

Example:

In the 35th month after her PASS became effective, a CR evaluated Phyllis Jones' plan to determine whether she had fulfilled her PASS during the first extension or whether a second extension was warranted. Phyllis' original PASS called for her to fulfill her PASS within 48 months during which she would complete her bachelor's degree in Marketing and become a sales manager for a consumer goods distributor.

Taking into consideration that she had projected the extension educational requirements for her occupational goal in her PASS, and that she had adhered to the provisions of the plan, the CR granted the 12-month extension and established a diary to mature in the 47th month of the PASS.

- 3) When the third diary matures, process a redetermination in accordance with SI 02305.050. Income excluded in accordance with a PASS will become countable the month after the month the PASS is terminated. Resources excluded in accordance with a PASS will become countable with the quarter following the quarter the PASS is terminated.

6. MUST BE CURRENT

A PASS must have a future date for completion. If a PASS is approved, exclusions based on a PASS can be applied effective with the date the individual began participating in occupational or training activity related to the PASS, but not earlier than the date of application.

7. THE INDIVIDUAL MUST BE PERFORMING IN ACCORDANCE WITH THE PROVISIONS OF THE PASS

Once a plan is established, the individual must perform in accordance with the provisions of the PASS. The individual can be deemed to be in accordance if he or she is awaiting the start of the next term of an established educational or vocational training program.

When a prolonged period of illness prevents an individual from engaging in the plan, document the file on an RC. Diary the case for a follow up contact and documentation every 30 days, not to exceed 3 months.

If at any time, for any reason, the individual is found not to be complying with the provisions of his or her PASS, follow SI 00870.075.

00870.050 Handling of Existing Plan

If the SSI applicant alleges he or she is already working, or being trained, under an existing rehabilitation plan that has not been reviewed by SSA, obtain a written copy of the plan or record the essential elements of the plan, as detailed in SI 00870.040.B, on an SSA-795 for the individual's signature. Take the following actions.

A. Individual is a VR or VA Client

If the individual indicates that he or she is participating in a VR or VA plan for rehabilitation, request the following on a DO Information Exchange Form (SI 00870.100, Exhibit 2):

1. Confirmation that the individual is a VR or VA client;
2. Identification of the occupational objective;

3. Identification of the amounts of income and resources being saved or disbursed as part of the plan and the purposes of the savings or disbursements; and
4. Verification of the date the plan indicates the individual will accomplish his or her occupational goal.

When this information has been obtained, determine if the information meets the criteria for PASS approval per SI 00870.040.B.

If the information meets the criteria, prepare a PASS and determination incorporating the information. then continue to develop the claims as instructed by SI 00870.060.

B. Individual is Not a VR or VA Client

If the individual indicates that he or she developed the plan or that it was developed by an agency or group other than VR or VA, review the plan carefully to identify:

1. A designated occupational objective;
2. The amounts of income and resources being conserved or disbursed toward fulfillment of the plan and the purposes of the savings and disbursements; and
3. The date it is anticipated that the individual

When the individual or someone other than VR or VA develops the PASS, a determination of the feasibility of the occupational objective, given the disability, must be made. The judgment as to the feasibility of the objective is usually made by the DO representative. If assistance is needed in determining the feasibility of the occupational objective because of the individual's disability, contact the local VR office for assistance (SI 00870.040). For the limited number of situations where rehabilitation services other than VR's or VA's are used, e.g., United Cerebral Palsy Foundation, contact the rehabilitative source regarding the feasibility question. In all non-VR or non-VA situations document the PASS determination with the evaluation of the feasibility of the occupational objective and the source of the information.

After the above information has been obtained, determine if the plan meets the criteria for approval per SI 00870.040.

Proceed to adjudicate the claim as instructed by SI 00870.060.

00870.060. Procedures after Approval or Disapproval of a Plan for Achieving Self-Support

A. Procedures for an Approved PASS

When it is determined that specific income/resources are to be excluded because of an approved plan, input this information to the system. If plan approval affects eligibility, the system input will be sufficient to generate a paragraph in the initial

award notice telling the individual the plan was approved. However, if the individual is already in payment status, the notice must be prepared manually. This notice can accompany the copy of the approved plan that is sent to the individual (SI 00870.065).

B. Procedures for a Disapproved PASS

If it is determined the PASS is not acceptable, the PASS should be reviewed to see if modifications would make it acceptable. If modifications would make the plan acceptable and the individual agrees to the modifications, prepare the PASS and proceed as in A. above. For assistance in modifying the plan, contact VR or any other appropriate source by telephone and document the conversation on a Report of Contact.

When it is determined a PASS cannot be approved, process the claim without the PASS exclusion and send a manually prepared notice to the individual explaining the reason for the plan's disapproval. In situations where the PASS exclusion affects eligibility, notify the DDS of the disapproval so medical development can be halted.

00870.065 Documentation

PASS has been fully adjudicated and input to the system, take the following steps to document the case. Using the original PASS and determination (SSA-553) and four copies:

- A. Forward a copy of the PASS and the written determination (SSA-553) of approval or disapproval to the claimant (advise the claimant if a copy will also be sent to VR or any other agency);
- B. If VR or another agency or group was involved in development of the plan, forward one copy of the PASS and written determination of approval or disapproval to the appropriate agency;
- C. Forward one copy of the PASS and written determination of approval or disapproval to your regional office/Assistance Programs Branch for their review;
- D. Place one copy of the PASS, written determination, and other pertinent documentation in the claims folder or redetermination folder;
- E. Maintain the original PASS, written determination, and other pertinent documentation in the DO file for reference.

CONTINUATION OF EXCLUSION

00820.070 Changes in an Approved PASS

Advise the recipient that he or she is responsible for reporting any changes in circumstances which would require changes in the approved PASS. If the individual reports a change in income/resources,

the plan should be reviewed and any necessary adjustments made. These changes may require amendments to the individual's plan or development of a new plan. In all cases where a PASS is amended or replaced by another plan, the amended or new plan (SI 00870.040.B.5) must be reviewed in the DO utilizing the evaluation criteria in SI 00870.040.

If the information pertaining to changes in an approved PASS or a new plan comes from a VR or VA agency, follow SI 00870.050.A. If the information comes from the individual or someone other than a VR or VA agency, follow SI 00870.050.B.

Substantive changes in an individual's PASS require written determination of approval or disapproval. If the changes involve a minor amendment to the plan. (i.e.. does not affect eligibility. SSI payment amount, or duration), make a brief reference to the affected part of the individual's PASS on a Report of Contact and associate the RC with the Client's DO PASS file. If the changes in the plan involve major revisions or a new plan, follow the procedures in CM 4S23 for special determination based on the criteria in SI 00870.040.

A. Changed PASS Approved

If the revised or new PASS is approved, funds conserved under the old plan may become part of the revised or new plan. Any change in the amount of income/resources to be excluded under the PASS results in a redetermination effective with the month the PASS is amended or replaced. Process the redetermination in accordance with SI 02305.005 ff.

The duration of the revised PASS may change. However, the plan's duration must still coincide with the maximum duration guidelines of SI 00870.040.B.5. If a new plan is established, i.e.. having no relation to the previous PASS, a new period is established.

B. Changed PASS Disapproved

If the revised or new PASS is disapproved, a redetermination is necessary effective with the month in which the individual is no longer performing in accordance with an approved plan (SI 00870.040.B.7). Process a redetermination in accordance with SI 02305.050 ff.

Even when the changed PASS is disapproved, the individual may continue to exclude income/resources under his or her old plan, provided he or she actually continues to perform in accordance with the provisions of the former plan and it continues to be an approved PASS per SI 00870.040 (i.e.. the duration of the PASS is still in effect).

00870.075 Approved PASS Not Followed

If, during the period that an individual has income/resources excluded under a PASS, he or she does not perform in accordance with the provisions of that plan for a period of more than 3 months (i.e.. rails to save or disburse for items listed in the plan or

fails to attend training contained in the PASS), the plan will be considered abandoned as of the time when performance ceased. However, if an individual notifies the DO that he or she is discontinuing participation in a PASS, it is not necessary to wait the 3 months. In either case, income excluded in accordance with a PASS will become countable the month following the month the PASS was abandoned. While resources excluded in accordance with a PASS will become countable with the quarter following the quarter the PASS was abandoned.

In all such cases, process a redetermination in accordance with SI 02305.050 ff.

00870.080 Fulfillment of a PASS

Fulfillment of a PASS occurs when:

- A. The individual has completed all steps of the PASS (i.e.. he or she has finished school/purchased the necessary equipment to start his or her business): or
- B. The individual becomes self-supporting during the pursuit of the occupational objectives: or
- C. The duration period allowed by the DO ends (e.g.. 18, 36, or 48 months). When a PASS is fulfilled, process a redetermination in accordance with SI 02305.050 ff.

00870.090 Suggested DO PASS

Information Summary Sheet
and Information Exchange
Form Formats

A checklist of critical elements could expedite collection of information for preparation of a plan. An example of such a checklist is provided in SI 00870.100, exhibit 1(a). Two additional exhibits illustrating PASS determinations are provided but no specific dates are used to maintain current exhibits (SI 00870.100. Exhibits 1(b). 1(c)).

Since SSA frequently requests assistance from VR. VA. and other service agencies in development of information relevant to evaluation of a proposed PASS, it expedites matters to establish a general information exchange format workable for the DO and the local staffs. The request forms should be fairly inclusive to avoid recontact as much as possible. Forms of this purpose should be developed locally to accommodate local procedures. It should be determined whether the VR or VA agency inquiries and the other agency inquiries require different procedures. Examples of possible formats are provided in Exhibits 2 and 3 of SI 00870.100.

In either case, control the individual's file for follow-up 15 days after the request is released to the agency.

00870.100 Exhibits of DO PASS
Information Summary Sheet
and Information Exchange
Form

- Exhibit 1(b). PASS Determination (Approval)
- Exhibit 1(c). PASS Determination (Disapproval)
- Exhibit 2. SSA DO Information Exchange Form
(VR Client)
- Exhibit 3. SSA DO Information Exchange Form
(Non VR Client)

Formats

- Exhibit 1(a). Checklist for Plans for Achieving Self-Support

Exhibit 1(a)-Checklist for Plans for Achieving Self-Support

Name _____ SSN _____

1. Objective of Plan:

(Explain in detail the ultimate occupational objective of the plan. Be specific, listing the actual objectives; e.g., training as a barber, with income expended for training and money saved to buy into or set up a shop; automobile mechanic, with current income spent for training and saved for future purchase of tools; school teacher with planned disbursements while obtaining the required training. List the steps necessary to achieve the occupational objective.)

2. Date the objective of the plan will be achieved: _____
(There must be a specific date for achievement; e.g., the date the training will be completed for the equipment will be purchased.)

3. Total amounts (money and property) necessary to achieve the objective of the plans.

4. In what manner is the individual working toward the objective of his plan?

5. (a) The amount of present savings (if any) set aside for the objective of the plan: _____

(b) Bank (or other institution) Name: _____

(c) Account Number _____

(d) Monthly income being saved for objective: _____

6. Disbursements made toward the fulfillment of plan:

(a) Amount(s) Date(s) _____
Items purchased _____ or Expenses paid _____

(b.) Planned disbursement(s) for fulfillment of plan.

(1) Amount(s) _____ Item(s) to be purchased _____ Date(s) _____ or

(2) Amount(s) _____ expenses to be paid Date(s) _____

7. Does the plan for achieving self-support appear feasible for the individual?

Signature _____ Title. _____

Date. _____

Exhibit 1(b)—PASS Determination (Approval) G-00870.100

Issue: Approval of Plan for Achieving Self-Support.

- Facts:
1. Mr. Sidel, a paraplegic, wants to establish a jewelry and watch repair shop.
 2. As written, the plan requires training in jewelry and watch repair.
 3. Mr. Sidel's level of education, high school graduate, and the sedentary nature of his proposed occupation support the feasibility of the occupational objective.
 4. the plan includes a 9 month training program and a 3 month period to locate and establish a shop. A diary is established for the 11th month of the plan.
 5. He will make three \$400.00 payments for his classes. The first payment is due when classes start, the second after 3 months, and the third after the 6th month. He will use current resources for the first payment and begin saving his title II benefits of \$325.00 and an anticipated accident settlement for the tuition and a down payment on shop equipment. This down payment will be approximately \$1200.00. Money should also be set aside for rent. It is anticipated monthly rental will run \$500.00.
 6. Mr. Sidel will deposit the title II benefits and the settlement in a separate account, Number 99999-90, at the Bank of Witman.
 7. Mr. Sidel's classes begin next month.

Determination: The criteria for establishment of a PASS are met.

The PASS is approved.

Authority: SI 00870.001-SI 00870.100

Exhibit 1(c).—PASS Determination (Disapproval) G-00870.100-2

Issue: Approval of a Plan for Achieving Self-Support.

- Facts:
1. Miss Chadwick, a secondary level teacher in special education, who is blind, requests development of a plan to obtain a master's degree in special education. The advance degree would increase her opportunities for administrative promotions.
 2. Miss Chadwick has some credits toward the degree. It would require 15 months for her to accomplish her goal.
 3. Since Miss Chadwick has achieved one degree, it is feasible she could attain another one.
 4. The funds for the education would come from her salary. The amount could be more quickly saved with the SSI income to meet daily needs.
 5. Miss Chadwick currently maintains a separate education account containing \$300.00, at the Liberty Savings Bank (account number 000-0000).

Determination: this proposal does not meet the criteria to establish a plan for achieving self support. Miss Chadwick is currently self-supporting in her teaching position and is only seeking to improve her prospects for advancement. This is not an appropriate use of a PASS.

Authority: SI 00870.001-SI 00870.100

Exhibit 2—SSA District Office Information Exchange Form (VR Client)

Section 1-Completed by DO

Date _____

TO: District Office of Vocational Rehabilitation (or Agency for the Blind)

Address		Zip Code
FROM: Claims Representative	Telephone	Extension

SSA District Office

Address		Zip Code
Individual's Name	Last	First
Social Security No.		Birthdate
Sex		
Address No. and Street	City	State
Zip Code	Nearest Phone	

Individual is also a title II (DIB, DAC, DWB) claimant, Allowed Denied Decision Pending

Individual advises us he (she) is receiving VR services and that he (she) has income and/or resources which should be excluded in determining eligibility for and/or amount of SSI payment because the income and/or resources are necessary for the fulfillment of a plan for achieving self-support. Please send us the following information about the individual's plan for achieving self-support. (Use separate sheet if necessary.)

Section 11—Completed by VR (or Agency for the Blind)

1. Objective of plan: Explain, in detail, the ultimate objective of the plan. It should be specific, listing the actual goal (e.g., training as a barber with income expending for training and money saved to buy into or set up a shop; automobile mechanic, with current income spent for training and/or saved for future purchase of tools; school teacher with planned disbursements while obtaining the required training.) List the steps necessary to achieve this goal.

2. When will the objective of this plan be achieved? _____

(There must be a specific date for achievement, i.e., month and year)

3. How is the individual working toward the objective of the plan? _____

4. (a) Money needed to achieve the occupational objective: _____

(b) Property needed to achieve objective:

Item	Amount of Value
1. _____	_____

S. Steps toward fulfillment of objective:

(a) Present savings set aside for the objective of the plan? _____

(b) Amount being saved monthly? _____

Exhibit 2 (Continued)

(c) Disbursements made toward fulfillment of the plan:

Item(s) purchased: _____ Amount(s): _____ Date(s) _____

Expense(s) paid _____ Amount(s) paid _____ Date(s) _____

(d) Planned future disbursements for fulfillment of plan:

Item(s) to be purchased: _____ Amount(s): _____ Date(s) _____

Expense(s) to be paid _____ Amount(s) paid _____ Date(s) _____

Signature _____

Title _____

Date _____

Exhibit 3--SSA District office Information Exchange Form (Non VR Client

Section 1.—Applicant/Beneficiary Identification

1. Name: _____

SSN: _____

Address: _____

Telephone: _____

Birthdate: _____

2. Title II Status

Allowed: _____ Denied: _____ Pending: _____

Claim No.: _____

Wage Earner (If Not Beneficiary) _____

3. Description of Disability/Limitations:

Section II—Self Support Plan

1. Occupational Objective: _____

2. Describe the Plan to Achieve the Occupational Objective:

3. Beginning Date of Plan: _____ Completion Date: _____

Month/Year

Month/Year

Extension of Plan Anticipated: Yes: _____ No: _____

If yes, Total Length of Plan: _____
(Months)

Exhibit 3 (Continued)

4. Monthly Expenditures Necessary to Fulfill the Plan. (Specify Type and Amount of Expenses):

A. VR Participation: Yes: _____ No: _____

Amount: _____

Description of Services Provided: _____

B. Other Income Utilized in Plan (Type and Amount): _____

C. Does The Individual Have Income Not Utilized in the Plan?

Yes: _____ No: _____ If Yes, List Type and Amount: _____

5. Is There a Savings Goal: Yes: _____ No: _____

A. What Is the Purpose of Savings: _____

B. Total Amount to Be Saved: _____

C. Monthly Amount to be Saved: _____

D. Where is the Money Being Saved:

Name of Institution: _____

Account No.: _____

Are these Savings co-mingled with other funds? Yes: _____ No: _____

(In order for savings to be excluded they must be kept in a separate account from any other funds).

E. Expenditures Toward the Savings Goal to Date: Amount(s): _____ Date(s): _____

Items Purchased to Fulfill Plan: _____

Signature Title Telephone Date

Agency

APPENDIX SIX

A Short Bibliography of Self-Advocacy Manuals and Articles

(Anyone who is interested in obtaining copies of the items listed or a more complete bibliography should contact People First, 2131 Capitol Avenue, Suite 100, Sacramento, California, 95816).

The Self-Advocacy Workbook, by Nancy E.S. Gardner, a product of Technical Assistance for Self-Advocacy Project, UAF-University of Kansas.

Self-Advocacy Training Modules I & II, by Trish Brown for Sonoma County Citizens Advocacy, Inc., under a grant from the Federal Department of Health and Welfare in 1979.

A Normalization and Development Instrument (ANDI), by Ann G. Flynn and Sandra K. Weiss, and An ANDI Workbook for Looking at Places People Live and Work, by William T. Allen and Nancy E. Gardner.

Workshop Manual, Program Analysis of Service Systems (PASS), by Responsive Systems Associates, Decatur, Georgia. (Be careful — this isn't the same "PASS" as what the Social Security Administration calls its "Plan for Achieving Self-Support" which is in Appendix Four.)

Way To Go, State of California, Departments of Health and Rehabilitation, 1978.

Self-Advocacy, Protection and Advocacy Agency, Honolulu, Hawaii.

Assertiveness, People First of Washington, Tacoma, Washington.

APPENDIX 7: A LIST OF REPORTS OF THE
STATE COUNCIL ON DEVELOPMENTAL DISABILITIES WHICH
RELATE TO RECOMMENDATIONS IN THIS REPORT

Recommendations About State Hospital System

- California Developmental Disabilities State Plan, 1984-86, Parts II and IV.

Recommendations About Community-Based Programs and Services

- California Developmental Disabilities State Plan, 1984-86, Parts II and IV
- Report on Quality Assurance in the Delivery of Services to Persons with Developmental Disabilities, 1984
- Monitoring the Quality of Life Experienced in Living Arrangements: A guide to Citizen Participation, 1981
- Action Plan for Eliminating Barriers and Obstacles to Developing and Sustaining Residential and Support Services, 1981
- Community: A Way to Self-Reliance, 1981
- Personalized Living: Homes for Californians with Special Developmental Needs, 1979

Recommendations About Services to Families of Persons with Developmental Disabilities

- California Developmental Disabilities State Plan, 1984-86, Parts II and IV
- Respite Services for Californians with Special Developmental Needs, 1982
- How to Start a Respite Program, 1982 (No. 1 of 3)
- Updating Your Respite Service, 1982 (No. 2 of 3)
- Parents' Guide to Effective Use of Respite Services, 1982 (No. 3 of 3)
- Proceedings: Conference to Plan for Respite Services in California

Recommendations About Vocational Assessment, Jobs, and Training

- California Developmental Disabilities State Plan, 1984-86, Parts II and IV
- Report on Wage Requirements and Performance Expectations of Sheltered Workshops Serving Adults with Developmental Disabilities, 1984
- Report on Alternative Reimbursement Mechanisms for Day Programs Serving Persons with Developmental Disabilities, 1983

Recommendations About Organizing and Training Consumers for Self-Advocacy

- California Developmental Disabilities State Plan, 1984-86, Part IV