

From Conversations To Actions Using The IPP

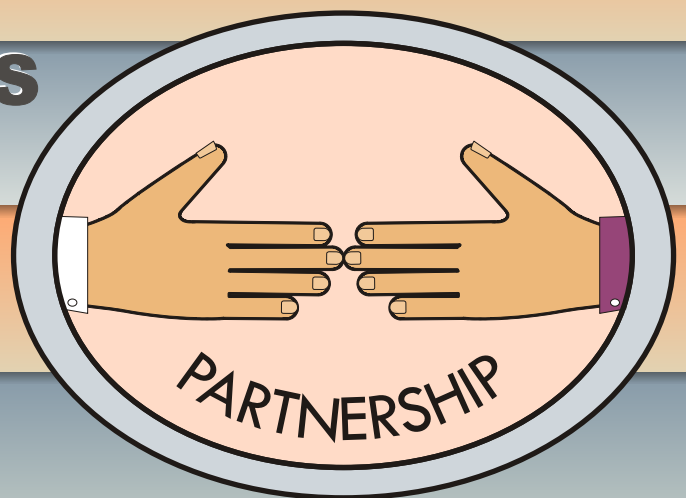
**Stories Of How People With
Developmental Disabilities
Have Used The
IPP (Individual Program Plan)
To Live Their Dreams**

MY LIFE - MY WAY

ACTIONS

MEETINGS

CONVERSATIONS





WHERE THE STORYTELLERS COME FROM



***Developmental Centers**

The Department Of Developmental Services (DDS)
Consumer Advisory Committee (CAC) Members
With Contributions From Members Of The Association Of
Regional Center Agencies (ARCA), Consumer Advisory Committee



INTRODUCTION



Leland Jacobs

MESSAGE FROM THE CAC PRESIDENT

Hello everybody!

I am the president of the Consumer Advisory Committee. My name is Leland Jacobs.

This booklet is to help you achieve your goals in life. The consumer friendly language and picture illustrations are used in this booklet to instruct you on how you can make positive changes in your life. I hope this booklet will help you in many ways, and remember “stick to it” and “go for it”.

I would like to send a special thanks to Mark Starford and Sherry Beamer for helping to get this booklet together.

Thank you.
Leland Jacobs



Donald Roberts,
Vice-President,
DDS CAC

PLEASE USE THIS BOOKLET FOR BETTER LIVES!

When the CAC members started talking about how services work for us, we learned that a lot of us did not have people working with us who listened to us. Some of us did not know how services are supposed to work. Some of us were having a hard time asking for an IPP meeting and services because workers do not check in on us very often. This just isn't enough. Problems come up. You really need people to help you. Life is hard.

So, we started training ourselves at the CAC meetings about our rights and we learned from each other how to use our IPPs to make our lives better. We taught other people with disabilities what we know, and many of us started to try out what we learned.

Our lives got better! Most of us got what we needed. We have people who care for us and listen to us and help us make our lives better.

If you are a person with a disability or a family member, we hope you will learn from this booklet that you have every right to ask for support from the regional center, and that your friends and community can help you. Think about what you want to do before your IPP meeting and talk at the meeting about what can happen, then make it happen!

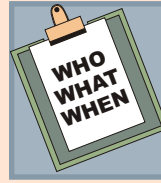
If you work with people with disabilities, we hope that you will use the stories in this book to learn from us what works and what does not work with IPPs. This way you can give us good services to help make our lives better.

Donald Roberts
Robert-donald@sbcglobal.net

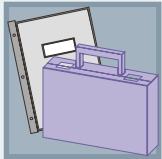
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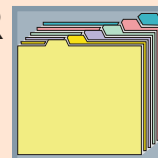
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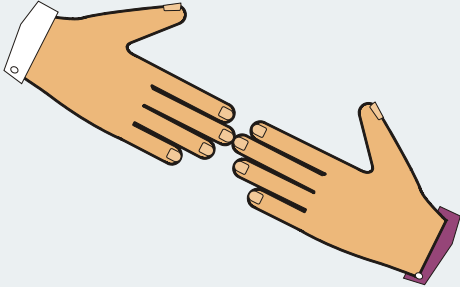


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HOW THE IPP WORKS

What is an IPP? (Individual Program Plan)



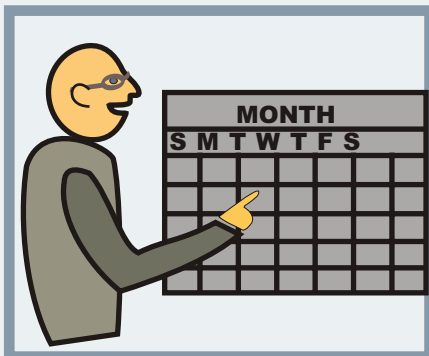
- The IPP is an agreement between you and the regional center.
- The IPP lists your goals, and the services and supports, that the regional center will help you with to meet your goals.

Who can be at your IPP meeting?



- Someone from the regional center who can promise to get the services you want and need. That person is usually the Service Coordinator.
- People who know and care about you.

How Does Your IPP Meeting Work?



- Your Service Coordinator will call you to have an IPP meeting at least every three years.
- You can ask for an IPP meeting at any time. Call your Service Coordinator to schedule the meeting.
- Your goals and services are discussed at the meeting.



HOW THE IPP WORKS

1



A **meeting** is planned with your Service Coordinator and anyone else you want at the meeting.

2



You will **talk** at the IPP meeting about your life goals and what you want and need to make them happen.

3



You and the people at your meeting will **agree** how they can help you meet your life goals or find people that can help you.

4



The agreements are **written** in your IPP in a way you can understand. Your Service Coordinator helps write the plan with your goals.

5



The Service Coordinator **sends** you a copy of your IPP for you to **sign** your name and for you to keep.

6



The Service Coordinator will work with you to make sure the agreements in your IPP are **followed.**



IPP PLANNING



Is there something new you would like to do?

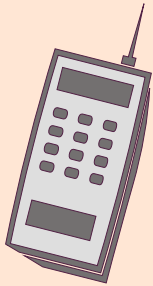
Is there something you would like to do differently?

Ideas can include: Where you live, work, school, family, socializing/relationships, making more money, or health.



MAKING IT HAPPEN

I will tell my ideas to:

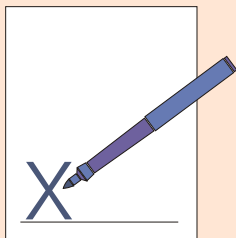


I will call my Service Coordinator by (date):



I will have an IPP meeting by (date):

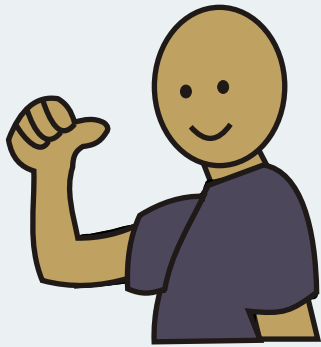
My new IPP will be ready by (date):



I will sign the new IPP by (date):



IPP PLANNING



A NEW GOAL:



OBJECTIVES (things I will do to reach my goal)

MY PLAN



What things will I do?

When

How Often

Who will support me?

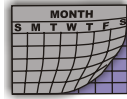
What will they do?



ELIZABETH "LIZ" LYONS



When Department of Rehabilitation Says No, Here's What You Do...



1 1/2 YEARS



I wanted to continue my education.



MY STORY

The Department of Rehabilitation helped me get an Associate degree in Child Development. Then I realized I was smart. So I wanted to go on with my education. I talked to my rehabilitation worker and she said she was going to talk to my counselor at the community college about going to the university. Then she said we never talked about that and it was not in my plan. She wanted me to get a job, but I told her I already was working two jobs at day care centers. She said I had to go to a job-training program to learn how to get a job or she would close my case. So she closed my case.

1. I wanted to continue my education.

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said we never talked about that and it was not in my plan. She wanted me to get a job, but I told her I already was working two jobs at day care centers. She said I had to go to a job-training program to learn how to get a job or she would close my case. So she closed my case.

2. My rehabilitation worker closed my case because she thought I should work more.

3. I went to the university to apply and again was connected to the Department of Rehabilitation. They wanted me to take some tests.

So I went to the university to see about getting an application. I talked to the disabled office. They said I could apply to pay for school as I was no longer with the Department of Rehabilitation. So I called Rehabilitation again about going to the university. I asked my regional center worker to come with me because sometimes I can't understand what is said or I have a hard time explaining

myself. This is when the trouble started. They wanted me to take some tests at a private testing agency.

I didn't mind taking the tests. The tests didn't have anything to do with the work I'm interested in. I asked for special accommodations and they didn't give them to me to take the test. I had to go for five days of testing from 8-4. Most of the time I sat around. Then I did things like open a door five times and moved blocks from one side of the room to the other. It was not good, and I told them. Their tests do not make sense in my opinion. I didn't agree with the results.

4. Tests said I should go to a sheltered workshop.

WORK AND SCHOOL

Then I went to the university again and talked to their counselor. She gave me a test that only took two days. The second tests showed that I could go to school but would need special accommodations like: a note taker, someone to read my tests to me, tutoring, and books on tape.

5. I didn't agree with the tests, so I took some tests through the university. The new tests said I could go to school.

The Department of Rehabilitation still said no to the university because they didn't think I could do it. We had to go to the main office and talk to a District Administrator and the supervisor from the Rehabilitation office. They also said no. I appealed again. They sent a mediator to meet with us. The regional center counselor came with me to all these meetings. They said no, but if I went back to their job workshop they would buy a tape recorder and spellchecker for me and then I should be done with the idea of college.

6. The Department of Rehabilitation still said I could not go to school. I had a hearing with an Administrative Law Judge.

I decided I'd come this far, I was going for the whole deal, win or lose. I had to get letters from my boss at the community college and the counselors at the community college and university. We had to go to a hearing with an Administrative Law Judge.


TIPS

You have to have a lot of patience.
You never are alone.

You don't have to do this by yourself.

Don't be afraid to ask people for help - like your rehabilitation and regional center workers, or any agencies in your life to help.

There are a lot of good people out there that can help you. I had a lot of good people who helped me.



I just won the case!

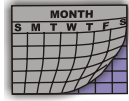




MARIA MARQUEZ



Going Back to School



2 - 4 YEARS



MY GOALS

To go back to school.
To communicate and write better.



MY STORY

Going back to school was in my IPP, but I didn't have a plan. I didn't write down what I need to do. Because of this I missed a deadline for school and had to wait another six months to sign up for school.

WHAT I DID AND WHAT HAPPENED



- I am in the self-determination pilot.
- I have a service broker who helps me with my goals.
- I direct my service budget.

I worked with my service broker to figure out the school schedules, the registration packet and grant applications.



I talked to my Service Coordinator about using my self-determination budget to have child care so I can go to school.

I talked to my family about a schedule that would work for me to go back to school.

Now I am signing up for school the next quarter. I am going to take one class at a time.

WORK AND SCHOOL



HOW I USE MY COMMUNITY

I use my community for almost everything:

- My girls take a lot of classes.
- We use the city swimming pool.
- We go to community events.

▼ TRAPS

I needed to talk to others, like my family, to figure out how to make my goals work for them too.

NOW

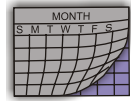
I am signing up for school the next quarter.
I am going to take one class at a time.





JOHN SAITTA

More Work...Please!



2 YEARS



MY GOALS

To find stable, full-time office work. I want to contribute, and be part of the community. I would like to make more than \$9/hour.



MY STORY

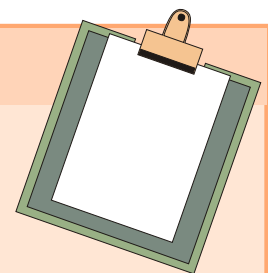
My sister works at Bank of America and she helped me find a good job there, working in the department that processed bank statements. I worked there for nine years part-time, making \$9/hour. I was laid off two years ago with all the changes the bank made. I asked my supported employment agency to help me find more work. It has been two years and I recently got some temporary part-time work. I am so frustrated it has taken this long for me to find more work! It is hard living in San Francisco on just my Social Security check. I have been sitting in my home for too long, waiting for work!



Ready for Work.

WHAT I DID AND WHAT HAPPENED

- I am receiving computer tutoring paid for by the Department of Rehabilitation so that I can have better computer skills for office work.
- I get nervous looking for work on my own, but it's time to try it again. I am going nuts inside the house.



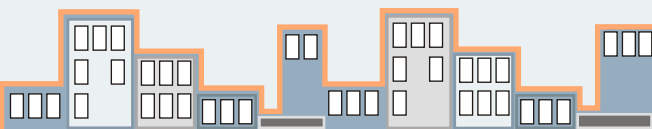
THE PLAN



- I have learned that the supported employment agency that I work with does not have good skills or contacts to find me an office job.
- Now the staff and my regional center Service Coordinator want me to go to an Integrated Work Study program. I'm hesitant. I'm not sure this is going to help.



A Display Of Awards That I've Received.



HOW I USE MY COMMUNITY

- I use public transportation all the time to get around.
- I am very involved as a leader in the disability community. I have received many awards for my work.

▼ TRAPS

- When I tried to look for work on my own to help the supported employment agency out, they didn't like it, so I stopped.
- Some supported employment staff didn't seem to have ideas about how to help me find the work I want.

NOW



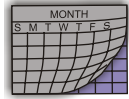
The supported employment agency has found me some temporary part-time work with a security company for conferences. If I don't have the kind of work I want by the end of the summer, I am going to talk to my Service Coordinator about a different plan.



HOWARD RODGERS



I Want Something Better



ONGOING



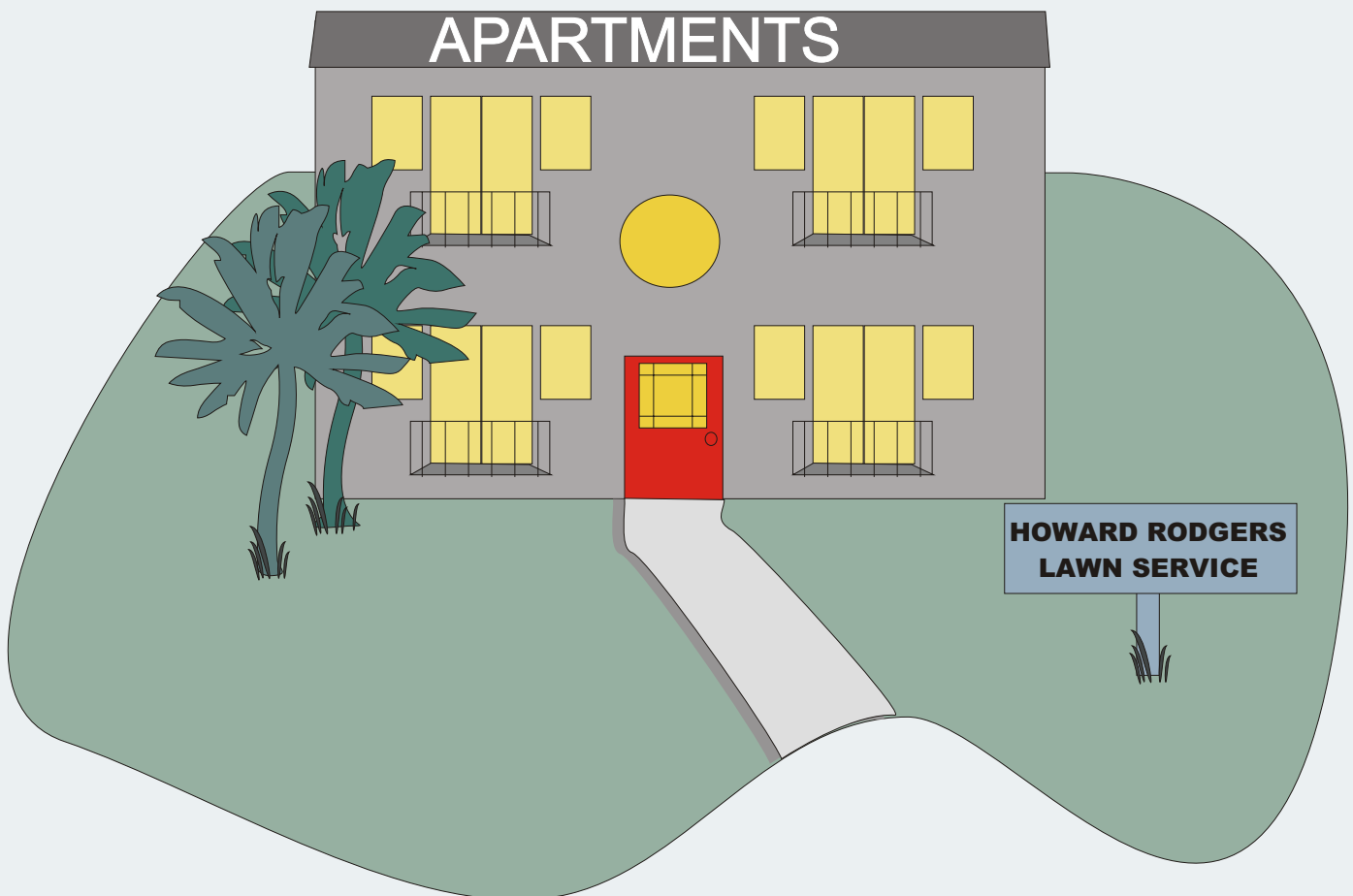
MY GOAL

My dream is to have my own business doing lawn work, not to do the lawns myself, but to own the business.



MY STORY

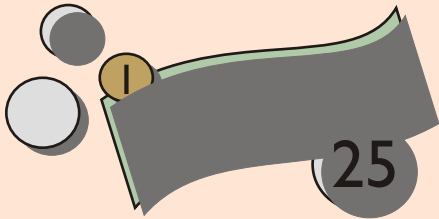
I want to own my own business. I've had a good advocacy job for eight years, but I'm not advancing and I'm not making enough money to take care of my family. I am 10 years from retirement. I used to cut lawns on my own. Now I'm thinking I'd like to own a lawn care business. The regional center is helping people with disabilities start businesses. I am checking it out.



WHAT I DID AND WHAT HAPPENED



I was getting aggravated at work. They gave me an opportunity. I like doing advocacy work and they created this job for me. But I've been doing this job for 8 years and I've not advanced. I walk by the employment board and there are always jobs open, but I don't meet the requirements. I have been all over this country speaking about advocacy, but I still don't make much money. I'm trying to figure out what to do next. I used to have a business cutting lawns and I did pretty well.



I'm 55 years old. I have 10 more good years of work. I want a pension to go along with my Social Security. I have an 85-year old mother that I take care of. That is aggravating too. I get paid every two weeks. After I go to make my car payment, I only have \$100 left in my pocket. Then I pay my electric bill and I have to ask the regional center for more money. The regional center helps me pay my bills because I had trouble with almost losing my SSI once.

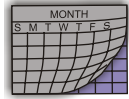
THE PLAN

I'd like to have something better for work. I talked to my Service Coordinator and the Consumer Advocate about this. Regional center has a state grant to help people start their own businesses. They are coming to see me soon.





I Can Do It Myself



ONGOING



MY STORY

I wanted to buy a home. I talked to my Service Coordinator and she referred me to an agency. I talked to them. It sounded like I could not buy a home because I do not make a lot of money. So I stopped trying. The way I live is OK now. I work, I drive and I have my own apartment.



At Home On My Own.

I help people with disabilities with issues in their lives like fighting for their rights, mobility and money management. I asked for help from the regional center to help me organize my advocacy work, but they said no. The regional center services are pre-planned. They don't really allow for your own input. So I decided to just take care of things on my own.

IPP STORIES



I am the Co-Chair of the People First of California Advocacy Committee. We are helping self-advocates take

action to make sure they have good services to be independent. We are helping people understand the state budget and the laws to vote on. People are very worried about what they hear about with services changing, like Medi-Cal health insurance, the Lanterman Act and In-Home Supportive Services. We get people to go out to rallies and write letters to say what we need. But there's still a "pickle"....



Doing My Work As An Advocate.

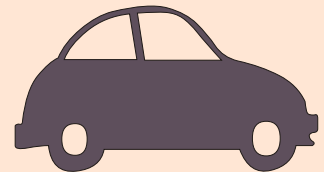
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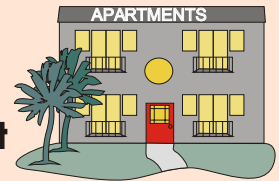
I work



I drive



I have my own apartment



I am an advocate for people



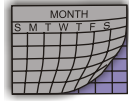
The way I live is OK





MICHAEL LONG

FIGHTING FOR SERVICES



1 YEAR



MY GOAL

1. I wanted to get supports around me so I would not have a chaotic life-style.
2. I want to be a tax-paying citizen and be a role model for people with developmental disabilities.



MY STORY

I was always fighting to receive services. My regional center always looked at my capabilities and not my needs since I have had a job for a long time and live independent. It has been a struggle to get the services I needed so I could avoid having trouble in my life and keep things from getting out of hand. I met an advocate who helped me organize myself and give me tips on how to communicate at meetings so I could be successful. Things are better today and I am learning new skills with the supports I am receiving from the regional center.

WHAT I DID AND WHAT HAPPENED

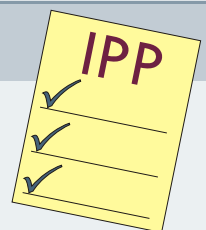
I learned to become assertive about my needs, not aggressive, when asking for services. I stopped yelling and fighting for services. I became calmer and less demanding with my service coordinator. I found an advocate that I trusted would help me. There were times when my advocate was like a social worker to show me new ways to act that would help me be more independent. It is taking time to learn new ways.



MY PLAN

To learn self-advocacy and communication skills that will help me be successful at an IPP meeting.

Design a person-centered plan with the help of a consultant that will guide my IPP meetings.



IPP STORIES

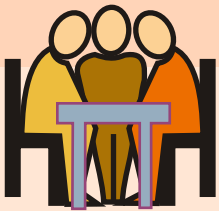
IPP PLANNING MEETINGS

I had pre-meetings before my IPP to practice what I was going to say and how I was going to talk assertively without being aggressive by role-playing.



TRAPS

- Not feeling successful.
- Being asked to justify needs to the regional center for continued funding.
- Personal growth takes time, and can be frustrating.



MY IPP MEETING

My meeting had many people that believed in me and were involved in my life. I had many people there for support, they included: a friend that I work with, an advocate, job coach, family members, and my regional center case manager. The meeting focused on my plan. People at my meeting helped me make a plan laying out responsibilities of who does what by when. The regional center agreed to fund supports in the community that helped me stay independent. My person centered plan consultant helped my service coordinator understand my needs and supports. I left my meeting feeling like people listened to me and what was important in my life.



HOW I USE THE COMMUNITY

- Depending on my friends and family for support.
- Keeping my job so I do not need any SSI. Living in my own home and driving myself to meetings.

NOW



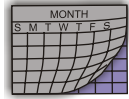
I am enjoying a more healthy and balanced life. With the support of my advocate and friends I have learned that it is the responsibility of each one of us to ask for help, and not depend on other people to do all our work. I am learning new skills at my job and at home.



JOHN GRABER



Honor the IPP!



2 YEARS...



MY GOAL

An electric door opener for my new apartment.



MY STORY

I was a client of one regional center for many years. I had been assessed and approved for an electric door opener for my apartment. I have cerebral palsy and my feet are fused by surgery. It is not good for me to reach across my body to do things like reach for doors, or to hold heavy things, like doors, with my legs. When I moved into another regional center area to live closer to my mother, I had to start the approval process over for the door opener, even though the law says when you move from one regional center to another your IPP is to follow you. The Office of Clients' Rights Advocacy is helping me with this case. I have a hearing with a judge scheduled in two months.



WHAT I DID AND WHAT HAPPENED



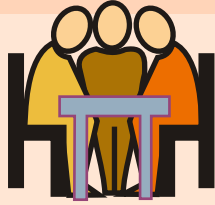
I live in a large Section 8 apartment building. Sometimes I use a rope to help me close the door. Sometimes I leave my door open when I leave. These are not good solutions for me.

I did what they said and I started the approval process over for my request for an electric door opener. I had to get another denial letter from Medi-Cal saying they would not pay for the door opener. I had to wait for another assessment from a therapist at the regional center. The regional center's therapist said I didn't need the door opener, but the old regional center said I did.

I am on the board of the Office of Client's Rights Advocacy Services. I called them to help me with this problem. They had an independent assessment completed for me, and their results said I did need a door opener, and one that only costs \$1,200 including installation.

MY IPP MEETINGS

- I did not feel that my new Service Coordinator advocated for me. We wasted a lot of time after I moved. This in part messed up some of the process because of timelines.
- My friends and family and my independent living and In-Home Supportive Services staff have helped me a lot with this, especially by sitting with me in meetings and giving me support.
- Sometimes I get so frustrated that it is hard for me to speak up like I need to in the IPP meetings.



TRAPS

- I trusted that the services would transfer between regional centers like the law says, but it's not true.
- Different therapists can come up with different recommendations.



HOW I USE THE COMMUNITY

I have been having some trouble trying to figure out how to get involved in my community. The city offers classes, but it is hard for me to go to because of the statewide volunteer boards I sit on. My friend is helping me figure out how to volunteer as a place to start.



Preparing For My Meeting



NYRON BATTLES

Every Picture Tells A Story



MY GOAL

I want to have the IPP made into a picture so people can understand it before they sign it.

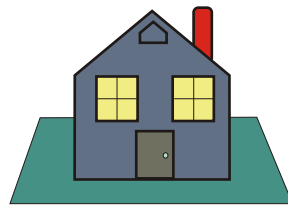


MY STORY

Many people, including me, cannot understand words and never learned to read. They sign their IPP and don't know what it says. Lots of us want to know what is in the IPP and have a copy we can understand at home. It helps me when my goals are in pictures and what will be done to make sure they happen.



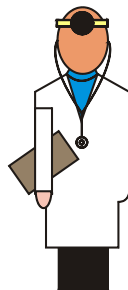
My IPP Goals October 2003



Goal #1
Continue living
in my own home



Goal #2
Participate in
community activities



Goal #3
Be in the
best health I can

Nyron Battles

I agree to these IPP goals



Meeting With Gabriel To
Talk About The IPP.

WHAT I DID AND WHAT HAPPENED

I met with my facilitator, Gabriel, and we talked about the IPP and he helped by putting the goals and objectives in pictures. I met with the regional center director and showed him that it is not easy to read the IPP without pictures. He was very friendly and helpful. I showed the IPP to the regional center CAC and they also liked the idea.



GOAL #3 Health

Be in the Best Health I Can

Objectives



Maintain and improve my health

- a Nurse will go to the doctor with me and explain things to me in plain language so I understand what I need to do
- stay healthy



I Will:

- learn about my body's needs and what foods to eat
- be responsible for maintaining good health
- learn what kind of exercise I can do safely
- walk as much as possible
- keep active



Maintain my mobility

- use crutches when I am at people's homes
- go bowling
- take the city bus for shopping
- eat less, be mobile = live longer



Improve my cholesterol level

- cut down on junk food and sweets
- eat vegetables
- use self control with food
- get a blood test annually
- keep my weight down



Meeting With The Regional Center Director.





DONALD ROBERTS

I Don't Look Down, I Look Up



1 1/2 YEARS



MY GOAL

1. Have a Supported Living Service that listens and provides services that are important to me, not what they think I should have.
2. People to hear what I am saying.
3. My service coordinator to care about me and return phone calls.
4. Be healthy.

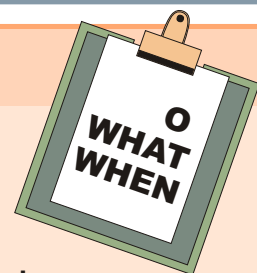


MY STORY

I live in the community and have a happy life. That isn't the way it was before. I was angry and got sick. I asked for support but people told me what to do and did not listen. Telephone calls were not returned and I felt alone and trapped. I was killing myself emotionally, spiritually and physically. Today it is different. I am healthier and have a worker who listens and provides the help I need. She helps me understand medications and balance my life so I don't overdo my advocacy work. I have an apartment in a nicer area; a dog named Restless, a partner, and I have been asked to go to Washington D.C. by my Mayor to talk about SSI. I am listened to and advocate for myself without being angry. I am more independent of the regional center than ever before.

WHAT I DID AND WHAT HAPPENED

- I made calls to the regional center, DDS, and an advocate.
- I asked the executive director to be my service coordinator because he would listen to me.
- I made a list of what I needed and had meetings with an advocate before my IPP.
- I got a new service coordinator.
- I quit my day program.
- I got involved in important projects: Memorial Project, Self Advocacy, and speaking about SSI rules.



THINGS THAT ARE HAPPENING

1. I am learning about what foods are good for me.
2. I have lost 37 pounds.
3. I am my own SSI payee.
4. I understand the medicines I am taking and the side effects.
5. I get calls from the regional center to see how I am doing.
6. I meet my worker over coffee to talk about my problems and get help.
7. I am more involved in supporting people's rights.



Krissi And Me
Enjoying Life.



NOW



I feel heard and supported by the regional center. People are listening to me and pay attention to what I say. They are not telling me what I should be doing. I am losing weight, feeling better and don't need to be angry.

▲ TIPS

- Use your community.
- Ask friends to take you to the store instead of using the door-to-door service.
- Walk places and meet people.
- Use a computer to learn about jobs, your rights and ways to stay healthy.

▼ TRAPS

- Waiting too long for someone to listen.
- Believing I was trapped in programs I did not want.
- Giving up on dreams and getting angry.



Speaking On Self-Advocacy.

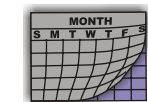


DAVID MILLER



Saving My Life

“I got very sick and almost died”



6 MONTHS



MY GOALS

- To stay independent in my own apartment like I have for 20 years, and be with my cat and friends.
- Be healthy and stay alive.
- Get extra help from support people.



MY STORY

- I went to the hospital many times and almost died.
- I had very few support hours and needed someone at home with me all the time in case I needed to go to the hospital.
- My service coordinator did not listen to me or my helper. The regional center told me to go to a skilled nursing home.

MY IPP MEETING

1. A regional center decision maker was there so I could get help.
2. I learned I had to fill out a “Needs Request Form” to show the regional center what I needed.
3. I had lots of friends at my meeting. There were 13 people at the meeting with 2 people on the phone.
4. I learned the laws and got help telling the regional center what I needed.
5. Good decisions were made so I can stay at home with extra support so I am safe and can continue my advocacy work.



Kris Is Helping Me Plan For My Meeting.

NOW



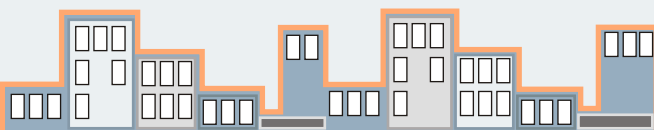
- I am healthy now, live at home with my cat and continue my activities in the community.
- Someone oversees all my services to make sure I am healthy.
- I have more hours for in-home support so I am safe.
- I have a new hospital bed and wheelchair so I can get around safely.
- I am active as an advocate and an “example” for others.

TRAPS

- Never be quiet when it is your life. Speak your mind!
- If you feel strongly about something you want, and the regional center doesn't want to do it, it's OK to disagree.
- Stand your ground, it's your life!



My First DDS CAC Meeting After Being Sick.



HOW I USE THE COMMUNITY

- I do shopping in my wheelchair at the local food market with help.
- I attend local meetings.
- I have good friends who help out when there is something that I need.

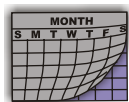




LELAND JACOBS

A Long Time To Wait For Something To Do

About Leland's friend from his self-advocacy group.



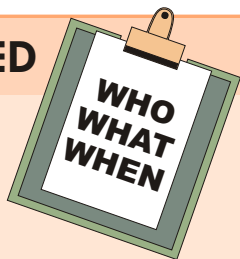
2 YEARS



MY STORY

My friend worked with me at a good job. On paydays someone would steal his check and no one could figure out who was doing it. His dad got frustrated and they decided that he shouldn't work anymore. Now he sits at home all day when he could be productive and earning some cash. My friend does not speak English very well.

WHAT HAPPENED



- My friend told his Service Coordinator about his decision and asked for a different job or day program.
- My friend waited a long time because he trusted his Service Coordinator, but nothing happened.
- My friend asked his independent living worker to help him find out what is going on.
- The regional center Service Coordinator said three months ago a new program was set up, but the name of the program was not mentioned and nothing has happened yet.

TRAPS

- Regional center Service Coordinators leave and you are not told. It takes a long time to get another worker.
- When there are state budget problems the services available become less creative.

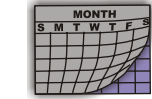
NOW



I am on the board of the regional center. I am tired of this. I am going to call the Executive Director and get something to change.

COMMUNITY LIVING

I'm Going To Drive!



6 MONTHS...



MY GOAL

To pass the written driving test to get my drivers license.

WHAT I DID AND WHAT HAPPENED

- I got the Driving Handbook from the Department of Motor Vehicles.
- I studied the handbook 4 times a week.
- I go out on drives with my staff to practice driving rules.
- I review the driving rules and take practice tests.



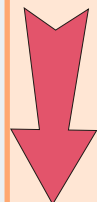
HOW I USE THE COMMUNITY

I am going to try to find some videos from the library to help me understand how to drive safely.

TIPS

I am also moving, so meeting this goal takes patience, time and commitment.

NOW



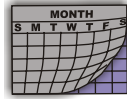
I took the test.
I didn't pass.
I will take it again in a few months.



KIM RUCKER



When the Partnership Works



1 1/2 YEARS



MY GOAL

I want a Select Comfort mattress that is an airbed that costs \$1,600. I have bad hips and this mattress helps me sleep because I don't feel as much pain.



MY STORY

I want a special mattress to help me sleep at night because I have a lot of pain in my hips. My health insurance would not pay for it. I found out how much the mattress would cost and found a mattress store that was willing to take payment from the regional center. I worked with the regional center on a plan where they would pay for half of the mattress

and I would pay for the other half. Because of the budget problem, the regional center is not able to help me with the mattress. But I am not worried. I will find another way to get the mattress.



The Bed I Need For My Hip Pain.

WHAT I DID AND WHAT HAPPENED

It took a while for me to explain to the medical group about why I needed the mattress. I got my doctor to write a letter about what I need. He recognizes that I know my body better than anyone about what I need. There is a lot of "red tape" with using health insurance to pay for things we need like this mattress. The insurance denied my request for the mattress.



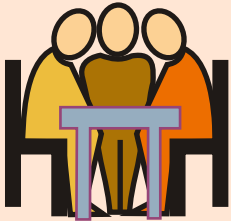
COMMUNITY LIVING

THE PLAN

I took a plan to the regional center where I would pay for half of the mattress and they would pay for the other half. I have done this before. I put together all the paperwork to give to the regional center for my request: the letter from the doctor, the insurance denial letter and the cost information from the mattress store.



PLANNING MEETINGS



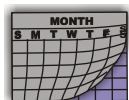
I found a mattress vendor who was willing to be paid by the regional center. My team worked together to put this plan together. My team is the regional center service coordinator, the independent living specialist, the doctor and my friend at that mattress store.

Now I thought my request would be accepted because I have worked with the regional center this way before. But because of the budget crisis my request for the regional center to pay for part of my mattress was turned down. But I am not worried; I will find another way. I have looked for a lot of my own services in the past, like special medical services and for recreation.





Clap Dancing



2 YEARS...



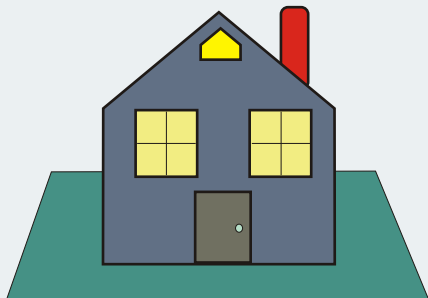
MY GOAL

- Twenty-four hour care so I can live in my apartment with my husband.
- Planning and supervising my services so that I can be safe and healthy.

My Story

MY STORY

I have a rare movement disorder that causes me to have seizure-like episodes, caused by stress and loud noises. These episodes can cause injury if I do not have people around me who can help me.



I have lived in many group homes with my husband Mike, but that is stressful for me, as I didn't always get good help. I now live in an apartment with Mike, but I need care 24-hours a day so that I am safe. The regional center didn't believe that I need 24-hour care. Sometimes I have lived in nursing homes so that I get the care I need.

I feel like the monkeys in the toy store when you clap your hands they start dancing. Because when you clap your hands, I have an episode. I don't want to. And the monkeys don't want to either. But we're programmed that way.



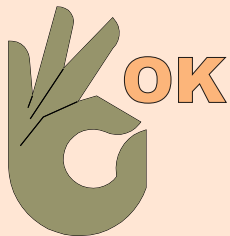
WHAT I DID AND WHAT HAPPENED



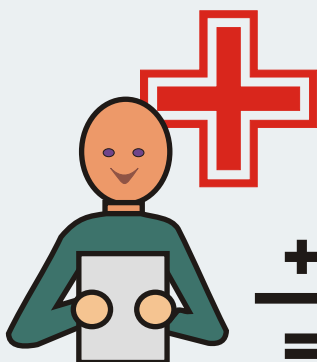
I worked with the area board and Protection and Advocacy to help me ask for twenty-four hour care.



I found a movement disorder specialist and started receiving treatment from him. I am healthier now. I now have a specialist who can provide good information about my disability.



I had LOTS of meetings and have done a lot of research on hiring and paying staff, etc.

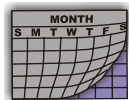


GOOD CARE
+ BEING SAFE AND HEALTHY

= MY LIFE - MY WAY



It's Not Fair!



4 MONTHS



MY GOAL

Stay in my apartment.

My Story

MY STORY

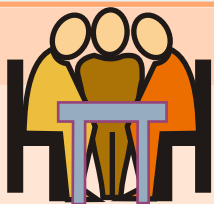
I have lived in my own apartment in supported living for 12 years. I have had roommates who helped me so I can be independent. My life became lonely with my last roommate and I was alone a lot. I got sick and went to my mother's house to get better. When I was there we found out that my roommate had taken things from me. We told her boss and she moved out. I also had to leave my apartment for over 2 months and stay at my mother's house until things could be straightened out. It was horrible!



I almost lost my home because of the problems. I was very angry about all this and that my things were taken. I wanted to move home and have a new roommate. I want a roommate who treats me better and helps me with things so I can be in the community, see friends and eat dinner with someone. I didn't like it when my roommate had friends over and made a lot of noise. I would be alone all weekend except when I went to my mother's house. I did not enjoy my life and felt trapped.



My New Team.



MEETINGS

My IPP meetings used to be terrible. I almost never talked and felt like people were saying things about me that made me feel bad, so I was quiet and angry. It was like I was the blame of all the things that were wrong and I had to always make changes. They didn't know what it was like to live in a bad situation and I was afraid to speak up. I got some help from the CAC and learned my rights and became even angrier. Our regional center's consumer advocate, Gary, started to come to my meetings and help me speak out and ask questions. I liked the help.

MY IPP MEETING

My last meeting was fun and people were caring. Gary asked a lot of questions and made sure things were OK for me. I need help standing up for myself and my new team is helping me. I don't think I need to be so upset anymore that I get sick and have to live somewhere else. I am learning to speak up because it is my life.



My Mother Has Been A Good Support.



NOW

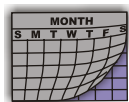
The regional center, my mother, Gary and an advocate helped me get a new roommate and a new agency that listens to me and we made a plan about what I want. It sure feels different. I am asked what I like to eat, how I want to spend my time, what is important in a roommate and new ways to help me protect my things so they will be safe. Everyone asks me questions and I tell them what I want. I like the new people and they respect me. I moved back to my own home and have dinners with people and will start seeing friends. I will not be alone like I was on weekends and nights.



My DDS CAC Facilitator, Marilyn, Helped Teach Me My Rights.



Home Sweet Home



1 YEAR



MY GOAL

To buy our own home.



MY STORY

I have wanted to buy a home for my husband Ozzie and me to live in. It was on my IPP as a goal for a long time but there never was a plan to help us find a house. We have always wanted our own home but did not know how to do it and how much money it would take. I have worked at a job for many years and started to save money so I did not need to depend on the regional center for everything. Our support person and friend, Wayne, taught us how to save money, pay our bills on time, eat good food and be healthy.

I am a DDS CAC member and the committee decided to talk to the community about the IPP and our rights. I looked at my IPP and thought about my goal of buying a home. Many months ago I created a team to help me understand all things that are needed to buy a house and how much money it would take. The team includes Wayne, my support staff, Sue, my service coordinator, Pete, from the regional center who knows about housing money, and an advocate.



Team: Pete, Ozzie, Betty, Sue and Wayne

Objectives

1. Get a copy of credit reports
2. Look into grant money for a down payment
3. Find new ways to make money
4. Look for private financing
5. Decide on the kind of house we want

We agree to do before next meeting:

| Team Member: Betty and Ozzie | | Team Member: Wayne | |
|-----------------------------------|------------|--|---------|
| | When | (ILS) INDEPENDENT LIVING SUPPORT | When |
| Start a regular saving program | this month | Help with getting credit reports | 1 week |
| Look for a new job | next month | Help me begin a saving program | 2 weeks |
| Learn about mortgage applications | this month | Teach me about buying a house | 4 weeks |
| Learn about grant money | this month | | |
| Team Member: Pete | | Team Member: Sue (Service Coordinator) | |
| HOUSING COALITION | When | REGIONAL CENTER | When |
| Look into county grant money | this month | Assist me scheduling meetings | ongoing |
| Put my name on the list | this month | Assist me with team follow up | ongoing |
| Look for houses | next month | Help me understand the process | ongoing |

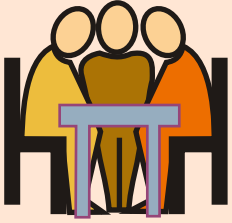
Notes and Agreements

| Team Facilitator: | When | Completed | Comments/notes |
|-------------------|------|-----------|----------------|
| | | | |
| | | | |
| | | | |

This is the form I use to make my meetings successful.

COMMUNITY LIVING

MEETINGS



My team met many times to talk about housing ideas. I was asked what kind of house I want and where I want to live. I learned about a mortgage and saving for repairs that a house needs. Wayne helped with creating a budget for us. When we all leave the meeting we agree to homework and when we will meet again. I've also learned about townhouses, first time buyer programs and low interest loans.



Team Budget Meeting

After many meetings and talks about budgets, I learned there isn't enough money to help us with a down payment because there is a budget problem in California. Also, costs for houses in our city have become very expensive and we may not be able to afford a house now. Pete explained that my name is on a list and when there is money I will be called. Until then we will live in our apartment.

With the help of our team I learned how to buy a house and why it is important to save money for the future. I still want a home for myself and Ozzie, but we will wait until we can save more money. Our team helped me think of other important goals and they will support me in having a great life and keep meeting with me.

▼ TRAPS

Forgetting about your dreams.

Expecting someone else will remember things when you don't.

NOW



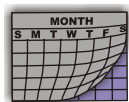
1. Do new things to our apartment so it will feel like a home, with the landlord's permission - such as make a small garden and paint our bedroom.
2. Save our money for a dream vacation, like going to Hawaii.
3. Find places to make speeches at big meetings where I can get paid and see new cities, like New York or Chicago.
4. Start a special savings account for a down payment.



PHA PRUM



Moving On To The Real World



A FEW MONTHS



MY GOAL

To live independently and have a job.



MY STORY

I was living with my parents. I did not have much independence. I wanted to live on my own and have a job. So, I told my regional center counselor and she put the goal on my IPP. She got me an In-Home Educator. They helped encourage me to tell my mom that I wanted to live on my own. At first I got a job in a sheltered workshop, but now I work as a client advocate in the Resource Center at a regional center. I now live in my own apartment with a roommate, and plan to live on my own soon.

WHAT I DID AND WHAT HAPPENED

I told my regional center counselor and she put the goal on my IPP.



THE PLAN



My support team, my regional center counselor and my In-Home Educator recommended that I should speak up for myself and tell my parents that I want to live independently.

PLANNING MEETINGS

My regional center counselor got me an In-Home Educator and a job at a sheltered workshop. Then my counselor told me about a job at the regional center as a client advocate.



MY IPP MEETING



My mom, my regional center counselor, and my In-Home Educator were there. I spoke up about wanting to live on my own. I listened to what it would take to make my goal possible.

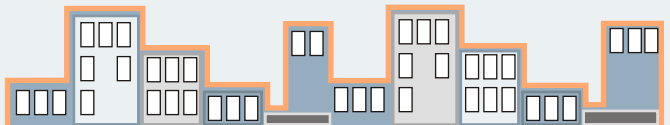
TIPS

My mom used to call me at least two to three times a day to have me move back in with her. But I told her that I have a lot of support people to help me out and be independent as possible.

NOW



It took me a couple of months to move out on my own. I live independently in the Home Ownership for Personal Empowerment (HOPE) program. I got a job at the regional center. I am able to go to work on my own near my home.



HOW I USE MY COMMUNITY

I am in various client advocate groups.

I do what I want on my own time and stay within my budget.

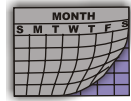
I use public transportation to get around, like going to Long Beach to see my family and to go to the Cambodian video store.





DEBBIE BEETER

Jump Start On A New Life



15 YEARS



MY GOAL

To live in supported living in my own apartment close to my sister and my family.



MY STORY

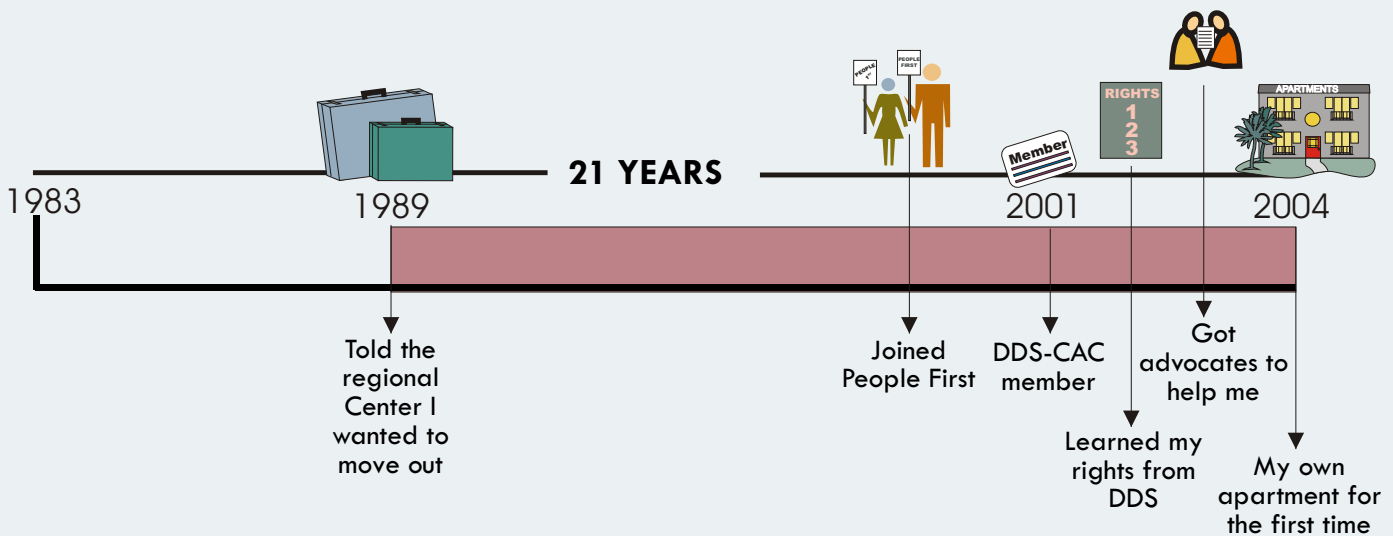
I have lived in a group home for 21 years. The home is for people with eating disorders and some

people have Prader Willi Syndrome. For 15 years I wanted to live in my own apartment. At my IPP meetings the case worker would not listen to me, they were “cut and dry,” we just signed papers and left. I was not listened to even when it was written down. No one helped me to make a plan. I have been angry for a long time about not being listened to by the case



My own kitchen.

worker. I was told I had to lose weight before I could have an apartment. That is not the law I learned!



Things started to change when I joined People First and learned about my rights. I am also a member of the DDS CAC and learned that I can move out and that the regional center should help me make a plan.

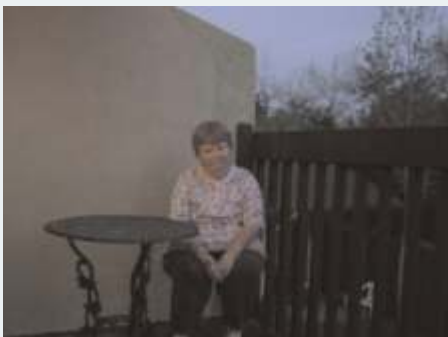
MY STORY CONTINUED

My sister came to the DDS CAC meetings, and she then believed that I could move out on my own. Then things started to change.

It's been a long struggle to get my own apartment. It took almost 2 years of meetings to make it happen. I also changed my job and can do things I like in my free time, like go to the library, the museum and meet new people. I am living in a city near my family and there is public transportation.

MEETINGS

There have been many meetings with the regional center and the (SLS) Supported Living Service agency. My sister and niece went to all the meetings and had to take time off work. I hope it is not this hard for other people who want their own life.



Relaxing on my balcony.

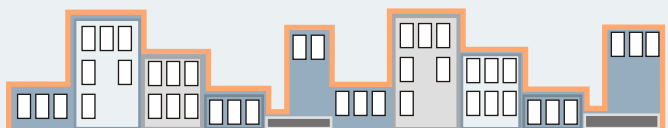
NOW



I am my own boss now for the first time. I am going on a diet, I get to eat my own food and have my own kitchen. I make my own dinner and have better food for lunch. No more bologna sandwiches and carrots.

TRAPS

- Make sure you understand and can read your IPP.
- Don't wait!
- Get support.
- Change case workers if they do not listen.



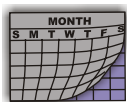
HOW I USE MY COMMUNITY

I go to the library.
I go shopping with help.



TAMMI BRADLEY

Fear Is Not An Option



30 DAYS



MY GOAL

To have good care 24 hours a day for me and my children that respect my choices about how I want to live my life.



MY STORY

In 2000, I started receiving supported living services for the first time. This allowed me to receive 24-hour care so that I can live in my home and take care of my two children.

In 2001, I started having disagreements with my service provider about unannounced visits to see how I'm doing, which I did not want. It is my right to not have them. Unfortunately, the supervisor threatened not to send an attendant to get me out of bed the next morning, if I did not allow the visit to take place at that moment! Even though I was afraid, I told her no and asked her to reschedule the visit and come back at another time. I filed a complaint using the Special Incident Reporting system with the regional center to inform them of the incident. The agency gave me a 30-day notice that they were terminating my care.



Again, I was afraid but with the help of my chore worker and service coordinator, we found another agency willing to take my case. The new agency's philosophy was, "Whatever It Takes!" I am allowed to choose what I want and to be who I am with this new company. For me, fear is not an option anymore!

MEETINGS



I did not want support from a company that would not allow me to make decisions. When the director from the new company came to my home, we evaluated each other. He asked questions about my needs and I asked questions about his company's philosophy. Taking notes about what we discussed helped me remember so that I could make my decision.

TRAPS

No matter how afraid you get, always remember that you are in charge and you can make your own decisions. Ask questions, take notes, and expect equal treatment for all aspects of your life.



HOW I USE MY COMMUNITY

Since I am unable to go out much, I utilize the Internet for research and to learn about things. I might want to look up a recipe, the hours of operation for the Easter Seals pool or when the next movie is playing at the theater. Many community organizations list their information and what services they offer on the Internet, so this can be a great resource.

NOW



Now: I live in my own home and have adequate attendant care so that I am able to care for my two children. The director of the new Supported Living Agency is very nice and accepts my right to choose.



DANIEL DAWKINS



Getting Out And Getting On With Life

Showing I Can Handle It Without Being Locked Up



MY GOAL

To live in my own apartment.

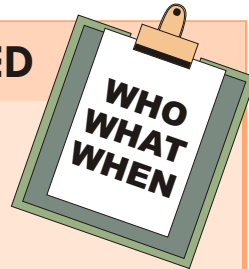


MY STORY

I've been around. I've been in jail and lived in institutions for 22 years. I don't have much freedom. I couldn't go to the grocery store and for coffee like I like to do. I had to work to get "off grounds" privileges by showing I can handle not getting into fights and ending up in jail when I go out. I talked to my Service Coordinator many times about wanting to move out, starting a year ago. They wanted me to go to a group home. I told them I wouldn't do it. I had to wait for the right opportunity to come along. I found an apartment. I will soon be living there.

WHAT I DID AND WHAT HAPPENED

One of the staff at the developmental center - her husband works for a supported living agency - the one I'll now be working with. He came out to talk to me. He told me about all the services and the rules and then I found an apartment next door. They are fixing it up for me so I can reach things, etc. They want me to have a roommate for a while someone without a disability to show me how to live on my own. I don't think I need it, but I'm going along with it.



MY IPP MEETING

My meeting was really a transition meeting to talk about what was going to happen next.



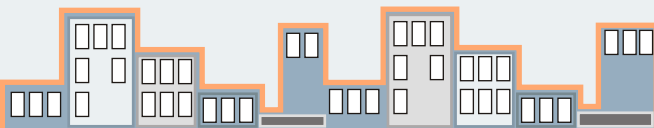
We worked out the details. We worked on an action plan like we do with the CAC.

PLANNING MEETINGS

The supported living staff comes to see me two times a week.



We go out for coffee or breakfast and get to know each other. They are also teaching me what it's going to be like on my own. For example, last week we talked about how we would be setting up medical appointments.



HOW I USE MY COMMUNITY

I take classes at the community college to learn how to use the computer, and to balance my checkbook. I use the computer to write letters and play games.

NOW



I will soon be moving out. I'm proud of the way I've handled things so that I can get out of here. I thought I'd never get out of here, but look at me!

▲ TIPS

To achieve your goal you have to do everything the staff says, and then you get referred to get out. You have to:

- watch your temper
- get up when staff says to
- brush your teeth
- go to school
- eat right
- go to scheduled medical appointments
- take your prescribed medications.



▼ TRAPS

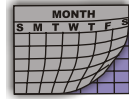
People think the institution is the last stop and you can't get out. But it's not true; it's just a way to get back on your feet so you can live in the community. It helps you cope with situations emotionally that get you in trouble.

I had to work on my mom to get her used to the idea. She wasn't too supportive. She thought I needed to stay in the institution for medical needs.



ROBERT MARGOLIN

Do You Know The Way To San Jose?



OVER 2 YEARS



MY GOAL

I want to leave the developmental center and live in San Jose in a group home with my own bedroom.



MY STORY

I am waiting to move back to the community. I told people at my IPP and the Developmental Center Administration for a long time that I wanted to move to San Jose. No one listened to me about moving until my friend Barbara,



Planning Meeting with Barbara.

the advisor for People First, helped me speak at my IPP meeting and make sure it was written down. I went to court and told the judge I wanted to live in the community. Many people were there to support me.

At my IPP and meetings with the Clinical Director, I said I wanted to practice making meals, house cleaning, and do my laundry in a Transition House before I leave the developmental center. I was told there isn't enough money and there wasn't a house for me to use. I am doing good and I make a lot of money at work. I am cooking once a month and go in a van to buy the food, but not in a Transition House. Things are getting better and people know I want to live in the community.

WHAT I DID AND WHAT HAPPENED

I made a video with my friend's help to tell people what I wanted. I had meetings with the Clinical Director and told her what I wanted. I told people at my IPP and People First meetings that I wanted to leave. I went to court three times and told the judge also. I am still waiting to move and do not practice my house chores in a Transition House. I think I am moving this summer.



DEVELOPMENTAL CENTER

PLANNING AND IPP MEETINGS

I made a book about me called "Live Your Dreams" and it was shown to people so they know what I want. I have had many meetings with the IPP team and they are helping me. Barbara has been a big help, she tells everyone that I want to leave and that I am ready to live in the community. The regional center service coordinator is helping to find a place for me to live and I want to visit San Jose soon so I can see things there before I move.



Having a dinner planning meeting.

▲ TIPS

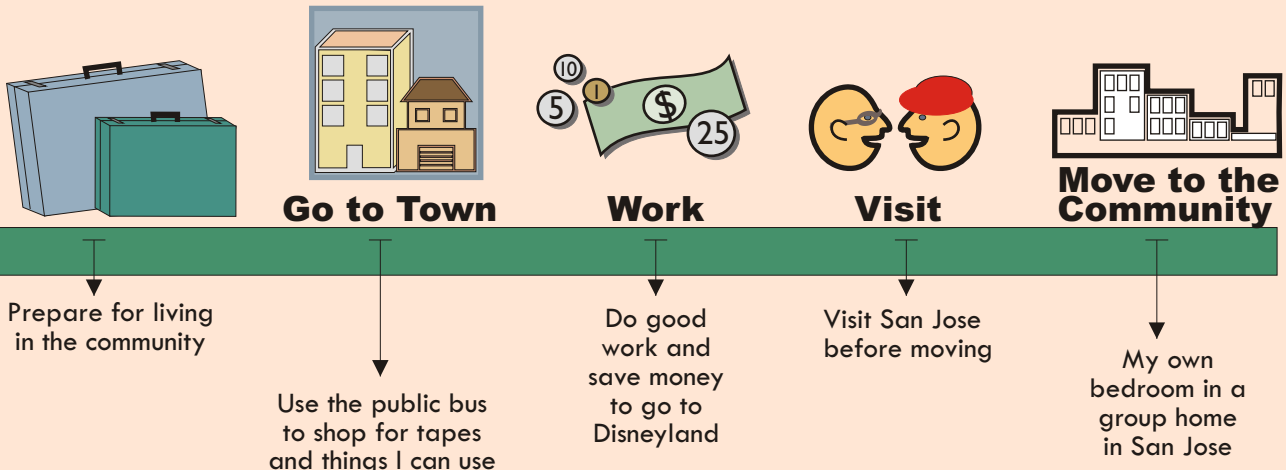
- Stay with it, have good behavior.
- Do things the right way and then you can leave.
- Have a good friend who believes you can do it.

▼ TRAPS

- People do not listen.
- People do not always believe in me.



Sacramento DDS CAC meeting in October.





ACKNOWLEDGMENTS

Our Vision Statement

“People with developmental disabilities in California will live their life the way they want”

INFORMATION ABOUT THE BOOKLET

The Department of Developmental Services (DDS) Consumer Advisory Committee (CAC) was started in 1992 by the DDS Director to give consumers a voice about how they receive services. The CAC gives DDS information about important issues that affect consumers in California and provides consumers information about things that DDS is doing.

In 2004, the Committee decided that they wanted to help make the IPPs work better for people with disabilities. They created some materials that describe how IPPs work and took that information to People First, Self-Advocacy groups and CAC meetings. The Association of Regional Center Agencies (ARCA) Consumer Advisory Committee agreed to help the DDS CAC create this booklet as well.

The DDS Consumer Advisory Committee thanks the following people and organizations that helped make this booklet possible:



- The California Department of Developmental Services
Cliff Allenby, Director
Carol Risley, Director, Office of Human Rights
Michael Long, Consumer Coordinator
- Association of Regional Center Agencies Consumer Advisory Committee
- Participating California People First and Self Advocacy groups
- Participating Regional Center Consumer Advisory Committees
- Board Resource Center
Sherry Beamer and Mark Starford, Co-Directors
- Donna Aikins Designs



TIPS FOR SUCCESS

PLANNING

1. Before your IPP meeting, meet with your support team and think about what you need and write it down.
2. Don't be afraid to call advocates.
3. Ask for IPPs in ways you can understand, for example on audio or videotape, with big print and simple words, with pictures, and/or in Braille.
4. Always read over your IPP before you agree to it and sign it.
5. Make sure everything that is promised is written down.
6. Keep checking with people who made promises to help so you get what you need. Don't be afraid to keep asking.
7. Invite people who care about you, like your friends, to the meeting.
8. Keep all your records, especially the ones you think you don't need.
9. Always write down who you talk to.
10. Because change in life will happen, think about situations that could happen to you and what you would need help with and include it in your IPP.



YOURSELF AND OTHERS

1. Don't carry your anger inside.
2. Ask for another service coordinator if yours doesn't help you. Go to the Director of the regional center if no one will help you.
3. Keep asking for what you need until someone listens to you.
4. Save your money.
5. Go to People First meetings and learn your rights.
6. Be assertive, not aggressive, in asking for what you want.
7. Keep an open mind to change because good things can happen, even if it is scary.
8. Get the community involved in what you want to do.
9. Be willing to do some of the work on your own. Don't expect that everyone is going to do everything for you.
10. Be open and honest and people will work with you.
11. Believe in yourself and that the life you want is possible.
12. Don't let people say bad things about you at the meeting.
13. Prove you are independent.

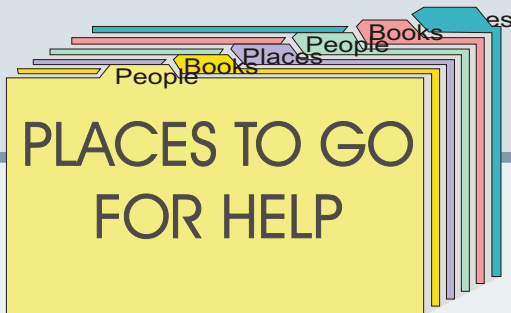


RESOURCES

INDIVIDUAL PROGRAM PLAN (I.P.P.) INFORMATION

“More than a Meeting; A Pocket Guide to the Person-Centered Individual Program Plan”, 2000, California Department of Developmental Services, PO Box 944202 Sacramento, CA 94244 916-654-1956 www.dds.ca.gov

“Your I.P.P. It's Not Just a Piece of Paper”, Protection and Advocacy, Inc. 100 Howe Avenue, Suite 185-N, Sacramento CA 95825 800-776-5746 www.pai-ca.org



SELF ADVOCACY AND RIGHTS

“A Consumers Guide to the Lanterman Act” 2001, California Department of Developmental Services, Office of Human Rights and Advocacy Services 1600 Ninth Street, Room 240 MS 2-15 Sacramento, CA 95814 916-654-1897. www.dds.ca.gov

“Your Rights” 2000, Protection and Advocacy, 100 Howe Avenue, Suite 185-N, Sacramento CA 95825 800-776-5746 www.pai-ca.org

“Community Conversations” 2003, Consumer Advisory Committee, California Department of Developmental Services, Office of Human Rights and Advocacy Services 1600 Ninth Street, Room 240, MS 2-15 Sacramento, CA 95814 916-654-1897, www.dds.ca.gov

“Beginning Steps to Self Advocacy” video training package, 1996, USC University Affiliated Program, Children's Hospital Los Angeles, PO Box 54700 Mailstop #53 Los Angeles, CA 90054-0700 323-669-2300, www.usc.edu/go/uap

People First of Washington Self-Advocacy materials. 932 6th Street Clarkston, WA 99403 800-758-1123

People First of California 1225 8th Street, Suite 210 Sacramento, CA 95814 916-552-6625 www.peoplefirstca.org

Board Resource Center (Mark Starford/Sherry Beamer) Facilitation Guide, 2003. A guide to support people with disabilities participate in governing boards. Post Office Box J Pacific Grove, CA 93950 866-75-SCILS, scils@aol.com