



# Recommendations for Satisfaction Surveys



Department of Developmental Services Consumer Advisory Committee  
2005

My Life, My Way



# INTRODUCTION

This year the CAC is continuing to talk about how services work for us. This year we are discussing the surveys we are asked to participate in about our satisfaction. We have a lot of different thoughts and ideas about this. This Satisfaction Guide turned out differently than we planned because of this. In this guide we try to help consumers understand what quality and satisfaction means to them, so when a surveyor calls they can give good information.

But first, we have a few thoughts for the leaders of the disability service system about satisfaction surveys and the quality of our lives. We are glad that you care about us and want to know that we are all right. We know most of you work hard for us, and have dedicated your lives to serve us.

As our friend and committee member Robert said while helping to make the Satisfaction Guide – “It’s My Life, My Way, not My Life, Your Way.” This means it’s each consumer’s right to choose the way they want to live their life. It’s a basic, simple concept. We each have people in our life who try to tell us what to do. We have to wake people up to make sure they give us good services, and listen and support us. From the food we eat and when we eat it, to where we live and who we spend time with, it is our life, and we need you to recognize that and help us to live our lives our way, not your way.

Everyone can communicate and participate in this process about a complicated idea like satisfaction and quality – we just need to find the right way to help people participate. We recommend that staff pay attention to people’s learning needs so they know



what kind of resources to use to help people participate – this could be a communication device, or extra time to spend with people to help them participate. We all learn differently – everyone does better when new ideas are in simple language with basic information. We need to stay with people until they start understanding what they are talking about. It may take years to understand and communicate what we feel. This has happened with many of our committee members and the complicated business that we review for DDS. Because understanding can be difficult for a lot of us, that doesn’t mean we should give up on helping people to understand this just because it’s difficult.

# PLEASE CONSIDER THESE THOUGHTS



Often times you depend on staff who work with us to answer the surveys for us if we cannot answer for ourselves. Or, you ask us to answer questions in front of staff. Or, surveyors are required to report any rights violations. Because of the difficult position this often puts us in, we think that your surveys will not be accurate

some of the time because we will not be able to give honest answers.

This is best described by one of our members:

*Most of us have loyalties to the people who take care of us. They feed us, give us our medication, have control of when and where we go, help us get our employment, sit in and control our IPPs, can decide what and how much we get to eat, control where we get to shop, what we get to buy, whether we can have a pet or not; basically they become a surrogate parent who may not love you*

*unconditionally. If you "tell" on them, they get mad at you. If they "tell" on you, you get in trouble. Either way you may get punished and may lose your independence. If this happens you will probably lose your friends, your contacts, your job, and may be too far away for any family to visit. I know; it happened to me several times after my safety overcame my loyalty and my fear of change. This loyalty problem kicks in even when you finally live independently because staff members are hard to find. If you can't be left alone, your fear of that overrules your concerns about your staff. (Tina Ewing-Wilson)*



# IDEAS



Here are some other ideas that we have discussed that we hope you will include in any work you do in the future to find out how satisfied we are with the services you provide for us.

Satisfaction and quality are big ideas that mean different things to people

depending on their life experience and the way they were raised. And, this thinking changes over time. This makes giving satisfaction surveys even more difficult to many of us who have had limited life experience and have trouble reading and understanding a lot of words and language. We think our IPPs are the best guide to ask questions about our satisfaction with our lives and services.

Government and service providers can never make us completely safe. The best chance that we have of being healthy, safe and satisfied with our life and our services is if we have people who care about us in our lives. When we have people who care about us, they will help make sure that we are happy, safe and healthy.

If we do not have people who care about us in our lives, this is what we need your help with!

We are shocked to learn that a lot of the information that has been collected from us is not being used because it is not considered to be good information, or staff aren't sure how to use it. We need to know that if we share this important information with you that you are going to use it to make services better for us. It is hard for us to let people we don't know come into our homes or call us up on the phone and ask us personal questions. We want to hear a report from you about how you use the information we give you.

We think there are simpler ways to know how we're doing. If you came to see us and spend a little time with us you would know if we lived in a safe place, were eating healthy food, had good medical care, liked the people who worked with us, have a good job if we choose to work, and have people in our lives who care about us. It might not be very scientific, but we think you can collect this kind of information from a lot of people and see some arrangements of services that work and those that need to be changed.

It would help us to participate better if the survey material was in alternate formats? We need time to consider the answers to the questions. When surveyors shoot a lot of questions at us, it's hard for us to speak up. Some alternative formats we recommend are audiotapes, computer files, "yes" or "no" or happy or sad face pictures for answers.

# LIFE EXPERIENCE WITH A DISABILITY

Here are a few thoughts we have about our life experience with a disability that will effect our participation with any survey you complete:



Our disabilities can make life really complicated. Sometimes our heads are “spinning.” Communication can be difficult, and can really mess things up. We need people who truly understand us to get the information we have in our heads out.

We each have our own ideas about what works for us. We need people to listen to our ideas, not theirs.

We need responsive services. We need to work together, talk to each other, and listen to each other.

Consumers have rights and need to be notified of their rights. Service providers need to be trained about our rights. Consumers need privacy. Staff should only be included if they are invited. It's rude for staff to listen in. Confidentiality is very important. When we need to report our staff, our words get mixed around some time. Staff need to get reprimanded when they do something wrong, not us.

We have a lot of irritation with the life changes that disability can bring pain, anger, exhaustion, depression. It makes us want to scream, or to fall asleep until it passes over us. We need you to hear our problems to support us because others don't always want to. We can be so tired of explaining our histories over and over again.



# QUALITY PRINCIPLES



In closing, here are some quality principles that we ask of the California service system for people with developmental disabilities, that we think fit nicely with the Quality Framework from the Center for

Medicaid Services that we learned about at the ARCA New Day conference -

Take the responsibility to do your work well. Take time with us; don't brush us off. We remember almost word for word what you tell us and say to us. We can tell that you don't always remember what you say to us. Don't just say what you think we want to hear. Do what you say you're to do.

We know we need to take responsibility for the quality of our own lives. We know we can't always choose the fun things to do instead of paying attention to changing our lives and making them better.

We need to work together - don't pass us around.

Keep good records.

We need more time with staff to be successful, but increasingly the people that work with us are spending less time with us. Our disabilities make us different than others, and we need some specialty understanding.

Don't tell us what to do; you can give us advice and direction, but we know what is best for us.



# FINAL THOUGHTS



We'd like to see some general standards of service for providers and the regional center. We feel that your practices benefit you more than us. You do similar work, you should have similar practices. Work for us first, and then take care

of how to organize the agency to serve us well.

Don't try to control our services for us. Always think of us positively, welcome our ideas about how we want to live our lives, believe in us and that we can do what we dream about doing.

We are your first customer. Make your policies open to us. We have the right to know.



We shouldn't have to bring lawyers in to get good services from the system.

Pay vendors on time.

Any business for us is about us. We should be welcome to help solve problems with services.



Make sure there are services for parents with disabilities. Being a parent is a very important job and there are few services for us.

Our experience is that service changes can be difficult, and aren't always planned well. We need your help with this. Whether it's a move from a developmental center to the community, from one regional center to another, or to a new service, the change is often not very smooth. This can cause us a lot of problems, and keeps us from being successful at what we need to do to live a better life.

## 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 DDS business.

In 2005, the Committee decided to increase its previous projects on the IPP by developing:

- Choice and Satisfaction Guides for people living in and leaving the developmental centers, and
- An Adaptation Guide for staff to present materials differently for people who do not read well.

These Guides were created by taking the material to People First and self-advocacy groups, CAC meetings and to the Association of Regional Center Agencies Consumer Advisory Committee.



**Consumer Advisory Committee 2005**

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