



Created by The California Department of Developmental Services' Consumer Advisory Committee

With Support from California Department of Developmental Services (DDS) Human Resources Research Institute (HSRI) Center for Human Services, University of California, Davis

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Cover art by Donald Roberts (1962 -2009)

Donald was a former member of the statewide Consumer Advisory Committee in California, Valley Mountain Regional Center Board of Directors, Olmstead Advisory Committee, California Memorial Project, and Self-Advocacy Council 6. Donald was dedicated to the empowerment of people with disabilities and expressed his experiences and dreams through his artwork.

What You Will Find in This Guide

Step 1: Some Things You Should Know Before You Start



What is a Survey? What is NCI? What is the User-Friendly Report?

Step 2: Getting Started with the NCI User-Friendly Report



Where Do You Get a Report? Why Get a Copy of the Report? What is Advocacy? Finding a Group

Step 3: Think – Plan – Do



First, Think Second, Plan Third, Do

Step 4: What Do the Numbers Mean?



Step 5: Think - What Did You Learn From the NCI Report?



What is Working Well?What Could Be Better?What to Do When Things are Different from What You Know?What Else Do You Need to Know?

Step 6: Plan - How are You Going to Use What You Learned?



What Steps Will We Need to Take? Things That are Working Well Things That Could Be Better

Page 24

Things That Could Be Better Things That are Different from What You Know Ideas for Making Things Better Sharing Your Ideas Telling Others What Support Do You Need? Setting Goals Sample Plan

Step 7: Do - Make It Happen, Follow Your Plan



Telling Others What You Learned Getting Ready To Share

Step 8: Learn From Others - How One Group Did It



Getting Started Getting Support

Page 33

Step 9: Tips and Traps



Being a Self-Advocate Is Not Always Easy Listen Stay Positive

Step 10: How Did You Do?



Did Your Plan Change Anything? What Did You Learn from Thinking, Planning, and Doing?

Other Information Words Used in This Report

Page 44

Step

Some Things You Should Know Before You Start

What is a survey?

A survey is a set of questions that gathers information about somebody or something.

There are many different surveys:

- Surveys that come in the mail
- Surveys you fill out on your own
- People may ask questions in front of a store or at home
- People might ask questions on the phone

I'd like to start by asking you about what you do during the day - if you have a job or other places that you go.					
PS-8	(Do you work at?)				
	Yes - code Question 2 as NOT APPLICABLE No - ask Question 2 Pon't know; no response, unclear response				
2)	If No, ask: Would you like to have a job in the community? 8 NOT APPLICABLE – has a job in the community 2 Yes 1 In-between 0 No 9 Don't know; no response, unclear response				
3)	Do you like working there? 8 NOT APPLICABLE - no job in the community 2 Yes 1 In-between 0 No 9 Don't know; no response, unclear response				

The questions are about something that people want to know. The questions could be about almost anything. It is not a test. No one has to answer the survey questions if they do not want to.

In California, you might be asked some questions about your services and supports for the National Core Indicators survey, also called NCI. The NCI helps the Department of Developmental Services (DDS) know how you feel about your supports. It helps DDS to know if people are getting the services they need.

What is NCI?

The NCI survey is used in many states¹. Questions are asked to people with intellectual and developmental disabilities and their families.

Questions are about:

- Life
- Home
- Community
- Services and supports

The answers from the questions

are called **data**. All of the answers (or data) are put into a report. The report helps states learn about what is working well and what could be better.

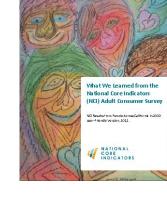
Click here or go to:

http://www.youtube.com/watch?v=yRo0XPqJyNo&list=UU-9-SZvXtauhegTgv7JmtPw to see a video about what to expect if you get asked to do the NCI survey.

What is the NCI User-Friendly Report?

The NCI User-Friendly Report shows answers to the survey questions that self-advocates in California said are the most important.

¹ Click <u>here</u> to visit the NCI website for additional information or go to: <u>http://www.nationalcoreindicators.org/</u>





Click <u>here</u> or go to the report at: <u>https://www.dds.ca.gov/QA/docs/adultConsumerSurvey2014.pdf</u>.

> The report shows the answers to the questions from all over California.

> > uestions like:

- Do you have a job?
- Do you get to visit your family whenever you want?

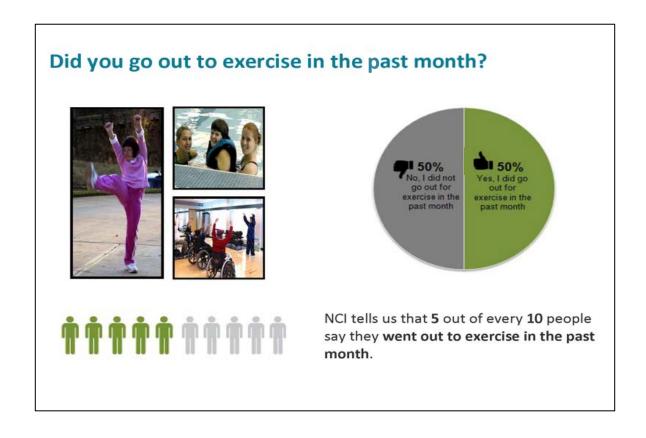


Yes answers may mean that things are working well.



No answers may mean things can be better.

The answers (or data) to each question are shown like this:



You can learn more about what the numbers mean in Step 4 beginning on page 16.

Step



Getting Started with the NCI User Friendly Report

Where Do You Get a Report?

You will find the report on the California DDS website. Click <u>here</u> to see a list of all the NCI User-Friendly Reports at: <u>http://www.dds.ca.gov/QA/index.cfm</u>

Why Get a Copy of the Report?

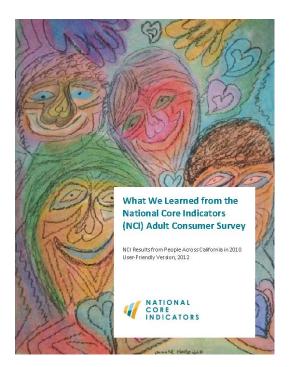
You can use the report to see what people in California think about their services and supports. This will help you **advocate** for services that are working well or that could be better.

What is Advocacy?

Advocacy is supporting something that you would like to be better. You could speak, write, or help others.

People advocate for:

- Better places to live
- Jobs
- Rights





Some people advocate by themselves. Tracey Mensch of Bakersfield advocates for better transportation. She meets with the Mayor to talk about how to make things better. Click <u>here</u> to see a video of Tracey with the Mayor or go to:

http://www.youtube.com/watch?v=3jqvbcqlltM&list=PLNPprD9qx QvHO63u1jY_gnK1BmgBA1LOp

Some people join a group. The DDS California Consumer Advisory Committee (CAC) is a group that tells DDS what is important to self-advocates. Click <u>here</u> to visit the CAC Consumer Corner or go to:

http://www.dds.ca.gov/ConsumerCorner/Home.cfm.



Finding a Group

You might want to join a group when you get a copy of the NCI User-Friendly Report. The California State Council on



Developmental Disabilities' has a list of groups at:

http://www.scdd.ca.gov/links.htm.

Or you can click on a link below to go to a group's website:

Area Boards on Developmental Disabilities

Autism Society

Family Resource Center Network of California

People First of California

Statewide Self-Advocacy Network

Supported Life Institute

The Arc of California

Step



Think - Plan - Do²

Think, Plan, Do can be used to help make decisions. Like what to do about a problem with a friend. Or, it could be used to help make a plan to buy something you want.

Here is how it might work for a group of self-advocates looking at the NCI User-Friendly Report. Click <u>here</u> to see a video on Think - Plan - Do, or go to:

https://www.youtube.com/watch?v=IPxs4If3yKE

First, Think

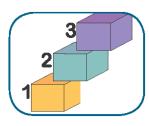
The group thought about what to do with the report.

Think - What do we want to do with the NCI Report?

- 1. Read the report.
- 2. Think about what is working well.
- 3. Think about what could be better.
- 4. Think about what we see is different from what we know.
- 5. Write down everything we learned.
- 6. Think about what we want to do with what we learned.

http://www.dds.ca.gov/ConsumerCorner/thinkplando/Making a Decision.pdf

² Click <u>here</u> to see a workbook called **Making a Decision** from the Office of Human Rights and Advocacy Services or go to:



Second, Plan

The group planned how to use what they learned and the support needed.

Plan – What steps will we need to take?

- 1. Decide what the most important things are to tell other people.
- 2. Add stories from our lives about what we learned.
- 3. Share ideas for making things better.
- 4. Write down what to talk about with other people.
- 5. Decide who we want to talk to about what we learned.
- 6. Decide how we will tell people.

Plan – What support do we need?

- **1. Support for reading and writing.**
- 2. Support for making a presentation about what we learned and what we know.
- 3. Thinking of ideas about how to make our plan work.
- 4. Help finding people we want to talk to.
- 5. Help making a plan with all of these steps.



Third, Do

Make it Happen. Follow Your Plan.

Our Plan

What we will do	Who will do it	By when
Read the report.	All of us	Two weeks
Ask someone to write	Our facilitator	
down our ideas for us.		
Talk about what is working	All of us	
well.		
Talk about what could be		
better.		
Talk about ideas for		
making things better.		
Talk to people about what		
we find.		

Step

What Do the Numbers Mean?

Take a look at the NCI User-Friendly Report. You will see pictures that show what the question is about. You will



also see what people said in three different ways:

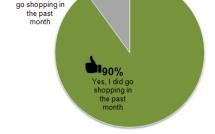
- Words
- Pie chart
- Stick people

Here is an example from the California User-Friendly Report.

10% No, I did not

Did you go shopping in the past month?







NCI tells us that **9** out of every **10** people went **shopping in the past month**.

This is the question that was asked:

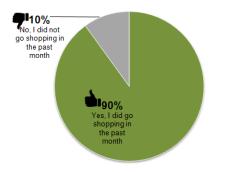
Did you go shopping in the past month?

This is the answer to the question in words:

NCI tells us that **9** out of every **10** people went shopping in the past month.

That means that for every 10 people who were asked, "Did you go shopping in the past month," 9 said yes.

This is the answer to the question using a pie chart:



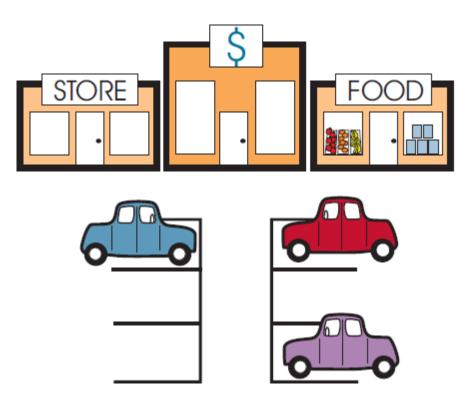
9 out of every 10 people (or 90%) who answered the question said **yes.** These are people who went shopping in the past month. The pie chart is green for yes. There is also a thumbs up, which means things are working well.

1 out of every 10 people (or 10%) who answered the question said **no.** These are people who **did not go shopping in the past month**. The pie chart is **gray** for **no**. There is also a thumbs down, which means things could be better.

This is the answer to the question using stick people:

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9 out of **10** people (or 90%) said **they went shopping in the past month**. Those are the stick people in **green**. The one person in **gray** did not go shopping.



Step



Think - What Did You Learn From the Report?

While you read the NCI User-Friendly Report, think about what you learned. We will show you some things from the California User-Friendly Report³. We will show you some ways to think about what you learned. Remember, you can use your own report and ask the same questions. You may have different answers.

What is Working Well?

What does **working well** mean to you? In the NCI User-Friendly Report it means things are going well for most people.

Things like:

- Living in a safe neighborhood
- Seeing friends whenever you want to
- Having enough privacy at home



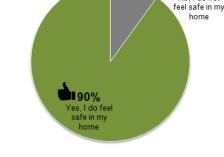
When you look at the report, decide what is working well.

³ Click <u>here</u> to see the report titled *What We Have Learned from the National Core Indicators Adult Consumer Survey: NCI results from people across California in 2010 User-Friendly Version, 2012 or go to:* <u>http://www.dds.ca.gov/QA/docs/what_we_learned.pdf</u>

Here is something **working well** in California.

For the question: Do you feel safe in your home?





10% No, I do not

*** * * * * * * * * * ***

NCI tells us that **9** out of every **10** people say they **feel safe in their home**.

9 out of every **10** people (or 90%) who answered the question said yes. These are people who feel safe at home. This shows that most people feel safe in their home. This is working well.

What Could Be Better?

What does **could be better** mean to you? In the NCI User-Friendly Report it means things could be better for most people. Like feeling safe in your home.

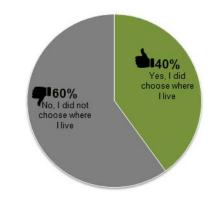


When you look at the report, decide what things *could be better*. Here is something that **could be better** in California.

For the question: Did you choose where you live?







NCI tells us that 6 out of every 10 people say they did not choose where they live.

6 out of every **10** people (or 60%) who answered the question said **no.** These are people who **did not choose where they live.** This shows that most people did not choose where they live. This could be better.

What to Do When Things are Different from What You Know? Sometimes, answers in the NCI User-Friendly Report are different from what you know.

Here is an example of what a group of self-advocates could do.

- Look at a copy of the NCI User-Friendly Report for the regional center area where you live. Click <u>here</u> to see a list of all the NCI User-Friendly Reports at: <u>http://www.dds.ca.gov/QA/index.cfm</u>
- It says that 9 out of 10 people (or 90%) can see their friends whenever they want to.



- That means that almost every person who answered the question answered **yes**.
- They think that is very high.
- They hear from others that a lot of people do not feel that way.



What do they do? They think about what is different.



They ask if it is different for:

- Where they live?
- The whole state?
- People who live in group homes?
- People who live on their own?

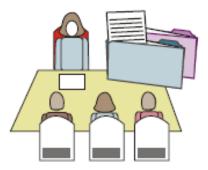
The answers might explain why 9 out of every of 10 people seems too high.

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What Else Do They Need to Know?

If they do not find out the reason why things seem to be different, they can:

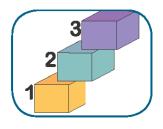
- Ask the people who wrote the report for more information.
- Go out and start collecting information from others.
- Write down what they learn.



Step



Plan – How Are You Going to Use What You Learned?



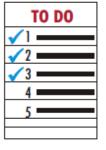
You have learned about things that are working well and things that could be better. Now you can make a plan to tell people about what you have learned. We talked about how to make a plan in Step 3.

What steps will you need to take?

- Decide what are the most important things to tell people.
- Add stories from your life about what you learned.
- Share ideas for making things better.
- Write down what to talk about with other people.
- Decide who to talk to about what you learned.
- How will you tell people?
- Decide what support you will nee.

The California CAC created a slide show to share their ideas. Let's look at some examples on the next page.





Things That are Working Well

First, the CAC talked about how to tell when things are working well. Then they looked at the NCI User-Friendly report.

They wrote down what was important. The box to the right shows what they learned.



What is Working Well?

The NCI report tells us that 9 of every 10 people they talked to say they:

- •Feel safe in their home.
- Have enough privacy at home.
- •Can see their friends when they want to.
- •Their staff at work, home and day program treat them with respect.

When you start to write your

ideas, look at all of the things in the report that are going well. Write them down. Write down why you think these things are important.

Things that could be better

The CAC talked about how to tell when things could be better. Then, they looked at the report.

They wrote down what was important. The box to the right shows what they learned.

Look at all of the things in the

Four Areas that are Important to Self- Advocates

What could be working better:

- Planning
- ∎Work
- ∎Wellness
- Transportation

report you think could be better. Write them down. Write down why you think these things are important.

Things that are Different from What You Know

The CAC talked about how to tell when things are different from what they know. Then, they looked at the report.

They wrote down what was important. The box to the right shows what they learned.



Transportation:

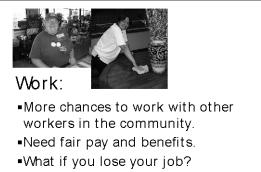
- •The NCI report is different from what we know in the community.
- We have talked to individuals all over the state.
- They say they have problems getting where they want to go.
- •You have to be able to get places if you want to be in the community.

Look at all of the things in the report you think are different from what you know. Write them down. Write down why you think these things are important.

Ideas for Making Things Better

Here are the ideas the CAC had about making things work better.

What are your ideas for making things better? Write them down. Write down why you think these things are important.



- It's hard to get back benefits (like social security).
- Why get a job?

Sharing Your Ideas

The CAC put their ideas in a slide show and a video to share with others. Here are some ways to share your ideas:

- Send letters
- Email
- Put on a website
- Give a slide show
- Make a video



Telling Others

Start sharing your ideas with the people you know. It might be a local area group. It might be the Mayor.

Here are some people you may tell:

- Advocates
- Families
- Service Providers
- City or County Officials
- Community Leaders
- Legislators
- State Agencies



What Support Do You Need?

If you need support, ask someone you know like a friend who can use the computer or someone who supports you.

You may need support:

- Reading and writing
- Using what you learned
- Making a plan
- Finding people you want to talk to
- Putting your ideas in a slide show, e-mail, or letter



Setting Goals

Look at your plan. Decide who will do each step. Decide when steps need to be finished.

Some things to think about:

- Should one or several people present?
- What day and time works best for everyone?
- How do you want to present?
- What equipment will you need?
- Do you want to give handouts?
- Should you write out the points you want to make?
- What kinds of questions will you be asked?
- Will you need to practice?





Sample Plan					
What we will do	Who will do it	By when			
Decide what support you	All of us	Two weeks			
need.					
Ask for the support you					
need.					
Decide what is working					
well.					
Decide what could be					
better.					
Decide what is different					
from what you know.					
Share ideas for making					
things better.					
Decide who you are going					
to tell.					
Decide how you are going					
to tell others.					

Step

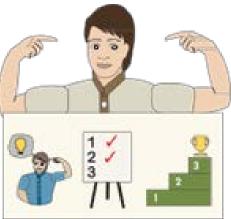
Do – Make It Happen, Follow Your Plan

Telling Others What You Learned

When you share people may want to ask you questions.

Here are some things you may be asked:

- What is working well?
- What are your ideas for making things better?
- How is the NCI report different from what you know?
- How is the NCI report the same as what you know?



• Can you tell me more about yourself or your group?

Getting Ready to Share

There are many ways to share. Here are some things to do if you are giving a presentation.



Before the day of the presentation:

- Arrange transportation
- Prepare equipment
- Prepare handouts
- Practice

The day of the presentation:

- Check on transportation
- Be early
- Dress neat and clean
- Bring equipment
- Bring handouts

During the presentation:⁴

CITY TRANSIT

- Relax
- Smile
- Stand or sit up straight
- Speak slowly
- Speak clearly
- Use a friendly voice
- Look at the people you are talking to





Here are some things <u>not</u> to do:

- Talk like you are mad
- Blame people for things
- Keep your arms crossed
- Stare

Remember people may disagree so don't take it personally.

⁴ Click <u>here</u> to see information on **Being Assertive**. ChildLine (2014) <u>https://www.childline.org.uk/explore/feelingsemotions/pages/being-assertive.aspx</u>

Everyone has the right to their own opinion.

Here's a Personal Story:



"I was doing a presentation and we showed a video. The video used the word disability in it. Someone in the audience got mad because it [the video] used that word. I said that we all have disabilities and we are all trying to make our lives better. We are trying to help everyone feel safe and be safe. The person said they were sorry and apologized to me."

– René Rodriguez, CAC Member

Step

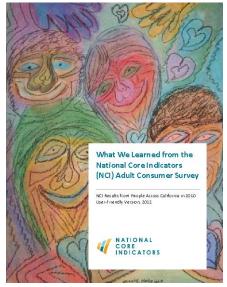


Learn From Others: How One Group Did It

Getting Started

The NCI User-Friendly Report was given to the CAC. This is a large committee made up of self-advocates from all over California.

The CAC set up a smaller committee called the NCI Subcommittee to read the report. They chose someone to be the chairperson of the subcommittee. Then they shared what they learned with the



CAC and the California NCI Stakeholder Group.

Here are pictures of the CAC NCI Subcommittee members:



Page 33



Krisi Franzone

Getting Support

The NCI Subcommittee asked for support. A self-advocate who works for the California Department of Developmental Services helped to set up meetings and do paperwork. Other staff from the state made materials and answered questions about the NCI User-Friendly Report.

Click here or go to

http://www.dds.ca.gov/ConsumerCorner/WaysComplex.cfm to see ideas on how to make meeting materials easy to understand. You can find it under the heading "Adaptation Samples."

Here are the steps the CAC followed to get the work done:

1. Reviewed the NCI User-Friendly Report

- Looked at the report by themselves or with a facilitator
- Circled the things in the report that are working well
- Circled the things in the report they thought could be better
- Wrote down everything they circled
- Made a list of things that are working well and things that could be better



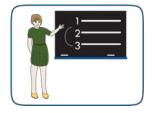
2. Made a Work Plan

- They decided:
 - $\circ~$ The goal of the group
 - o How often they would meet
 - $\circ~$ Who would do what and by when
 - To make a video and a slide show for others
 - When they would finish the video and the slide show

3. Talked About the Things They Circled

- They picked the top things that:
 - o Are working well
 - o Could be better
- They decided what to say about:
 - o Things that are working well
 - o Things that could be better
 - Things that are different from what they know
- They had questions about transportation:
 - What they knew was different things from what was in the report
 - They asked staff from the state for more information
 - They asked other self-advocates about what they know







4. Made a Video and a Slide Show

- They included:
 - o Things that are working well
 - o Things that could be better
 - o Things that are different from what they know
 - o Ideas for making things better

5. Shared a Video and a Slide Show

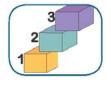
- They shared their slide show with the CAC
- The whole committee talked about it

6. They presented to the California NCI Stakeholder Group

- The chairperson presented it
- Click <u>here</u> or go to <u>http://www.youtube.com/watch?v=x2K1uT4pKb4&list</u> <u>=UU-9-SZvXtauhegTgv7JmtPw</u> to see a video about the presentation.

7. Next Steps

- Plan who else to show the video and slide show to
- Present to whoever asks
- In six months, talk about:
 - $\circ~$ The presentations that were made
 - o Did anything change?
 - What is working well and what could be better?



National Core Indicators 10 Easy Steps

User-Friendly Guide

Step



Tips and Traps

Being a Self-Advocate is Not Always Easy

Being a self-advocate is an important job. Like any job, it is not always easy. Some things are hard to do. These things are traps. A trap is a time when you may need help. Things like getting people to listen



to you, or working to change something.

When that happens, you could meet with your group again. Here are some tips that might help your group work together.

When things are hard:

- Sit so everyone can see each other
- Have a facilitator there to help
- Have something to write down your ideas so everyone can see them. You can use:
 - o Dry erase markers and a white board
 - o Big paper and markers
- Say what the trap is like "no one will listen to us"
- Let everyone talk
- Use your best listening skills
- Come up with as many ideas as you can

National Core Indicators 10 Easy Steps

User-Friendly Guide

- Write them down
- No idea is a bad idea
- Be respectful of other people's ideas
- When you are finished, take a break
- Come back and look at your ideas
- Decide the best 2 or 3 ways to start again
- Make a new plan
- Make it happen and follow your plan





Click here or go to

http://www.youtube.com/watch?v=vcAUKKvbuh0&list=P LNPprD9qxQvHO63u1jY_gnK1BmgBA1LOp to see a video of how Krisi Franzone gets help when she hits a trap.

Listen

When you are working with a group it is important to listen. Here are some tips to help make sure you are listening:

- Make eye contact
- Face the person who is talking
- Think about what they are saying



• If you have questions, wait to ask them until the person is done talking

Stay Positive

Some changes take a long time. It could take months or even years. It may be hard to keep going, but you can do it. Try to stay positive. Remember, you are working to make things better.

Here are some more tips to help along the way:

- Be persistent
- Be kind
- Build relationships with community members
- Encourage others
- Share ideas
- Help find a solution



Here's a Personal Story:



I was having problems with my doctor listening to me. I decided I would do a little research on what my symptoms were; I wasn't feeling well and was losing weight. I wrote down notes on my phone so I would have them to review with my doctor. He never seemed to take me seriously when I would ask questions. He still wasn't listening to me. The next time I went I had done

some additional research on my symptoms and had seen a commercial that reinforced what I thought was wrong. I also took along reinforcements – my SLS worker. The doctor was surprised at this and how prepared I was for my visit. I requested blood tests and the doctor finally agreed to listen to me. It's important to speak up for yourself to your doctor and let him know how you are feeling.

- Eugenia Jones, CAC Member

Here's a Personal Story:



There are several ways that I advocate for myself. For example, I was with an ILS agency for 20 years. The agency wasn't providing me the services that I needed in order to maintain my living situation in my own home. So I did almost everything on my own. By doing things on my own, I made some bad decisions for myself that had

bad results for me and others. I started attending Self Advocacy meetings and learned that I didn't have to live with poor services. Through these groups I built a true support team. I changed agencies and my life has changed for the better. Now I feel like I am in control of my life. I'm able to make responsible and wise decisions. I'm also able to think things through, and I can depend on my advocacy team to listen to me without trying to make my decisions for me. I'm grateful for my life. It is a beautiful life worth living and I feel very secure now that I have been able to build a support team that supports me so much so that I am able to be a support to myself and others.

- Esther Kelsey, CAC Member

Step



Did Your Plan Change Anything?

Now it is time to look at what happened. This is called an evaluation. Some questions to ask are:

- Did any changes happen after you presented your ideas?
- Are you still working on them?
- Is it time to make a new plan?

Our Plan

What we will do	Who will do it	By when
Make the presentation.	All of us	Two weeks
Use Step 6 to help us.		
Ask someone to help put it	Our facilitator	
on the computer.		
Make a list of people to		
send it to.		
Ask people if they would		
like us to present what we		
learned.		
Make a schedule of places		
to present		

What Did You Learn from Thinking, Planning, and Doing?

- What did you learn about doing this work?
- What worked well?
- Would you do anything different next time?
- Which steps would you change and why?



Other Information

Words Used in This Report

Advocacy – supporting something that you would like to be better

Committee – a group of people working together

Data – information from the questions

Decision – making up your mind about something

Evaluation – to look at carefully; think about what worked well and what could be better

Facilitator – person who supports someone else or leads a group

National Core Indicators – a survey that is used to find out how individuals with developmental disabilities feel about the services and supports they receive

Self-Advocate – person who speaks up for themselves or others

Stakeholder – a person or group who has the same interest

Subcommittee – a smaller group of people that are part of a larger group working together



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User-Friendly Guide

Created by: Consumer Advisory Committee to the California Department of Developmental Services

2014

MY LIFE, MY WAY

