

2013-
14

Statewide Self Advocacy Network

Annual Report

October 1, 2013- September 30, 2014



State Council on Developmental Disabilities
1507 21st Street, Suite 210
Sacramento CA 95811
916-322-8481

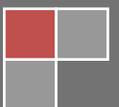


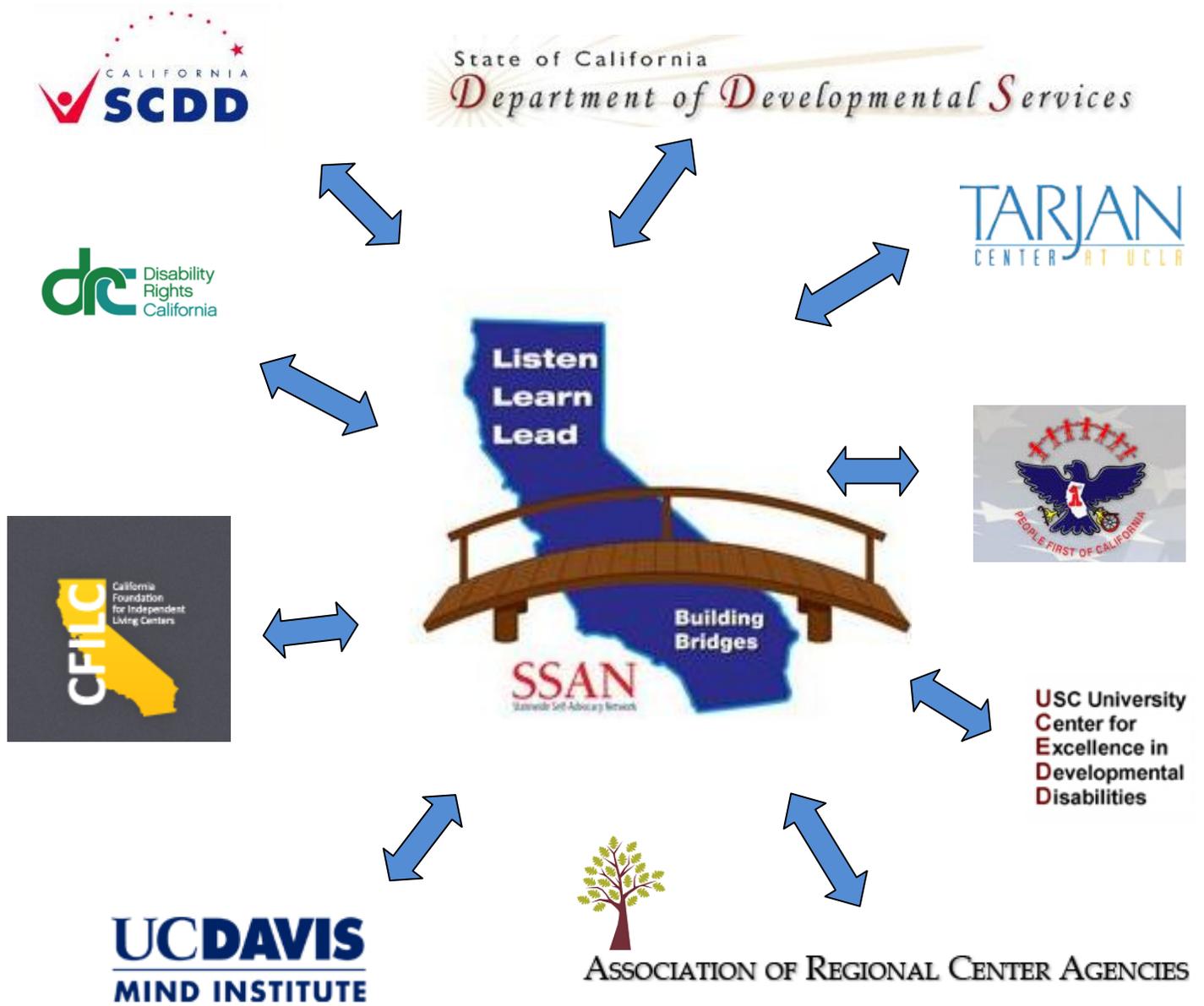
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Mission Statement

The Statewide Self Advocacy Network (SSAN) promotes leadership and builds bridges that strengthen advocacy among disability communities by focusing on policy change.



Message from SSAN Chair

There is a great deal of future opportunity for the Statewide Self Advocacy Network to move forward in a positive direction. We have a voice! The strength of our voice needs to be heard by all individuals in California. Our job is to make their voice loud as well. As we strengthen those voices they will be empowered to speak up and express what is needed to improve their lives.

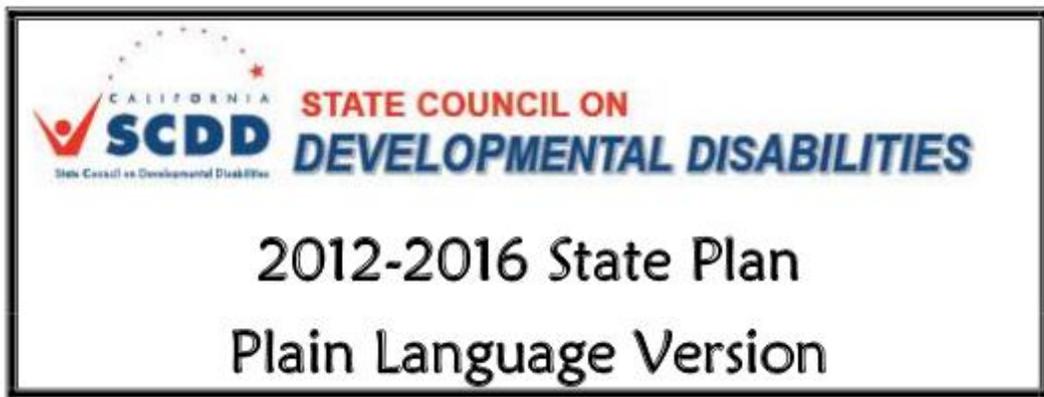


Advocacy is what drives me. Not only am I to advocate for myself, but I have a mission to teach others with disabilities to advocate for themselves. It is not always easy to be an advocate, sometimes we make people uncomfortable by insisting on change, by insisting on self-determination. I am okay with creating that feeling of discomfort; it is what an advocate is supposed to do.

Here are the needs that I will address:

- We need to promote leadership development.
- We need to promote inter-agency collaboration.
- We need to be representatives at the table of the policy makers.
- We need to *be* the policy makers.

Cheryl Hewitt
SSAN Chair



SCDD Self Advocacy Goal

Goal #1

Individuals with developmental disabilities get the help they need to be a part of the community and control their lives

Objectives

1a) The Council will support a statewide self-advocacy network.

1b) The Council will help start 23 new self-advocacy groups in different parts of the State. We will help 370 more people be part of self advocacy groups.

1c) The Council will teach at least 2800 self-advocates about their rights.

1d) The Council will help at least 31 groups of youth and people with different disabilities to have better leaders.

1e) At least 125 individuals with developmental disabilities will be trained so they can train other people with developmental disabilities to become leaders.

SSAN Members 2013-2014

- Region 1 – Willie West
- Region 2 – Charles Horne-Nutt
- Region 3 – Jennifer Allen
- Region 4 – Michael Arbios
- Region 5 – Regina Woodliff
- Region 6 – Robert Balderama
- Region 7 – Cheryl Hewitt
- Region 8 – Rebecca Donabed
- Region 9 – Sigrid Bremer
- Region 10 – Julie Gaona
- Region 11 – Kyle Minnis
- Region 12 – Chris Rogel
- Region 13 – Trena Wade
- Association of Regional Center Agencies – Jesse Padilla & Desiree Boykin
- California Foundation of Independent Living Centers – Ted Jackson
- Department of Developmental Services – Nicole Patterson
- Disability Rights California – Daniel Meadows
- People First of California – Joseph Meadours
- State Council on Developmental Disabilities – David Forderer
- University Center on Excellence in Developmental Disabilities (UCEDD) UC Davis MIND Institute – Robert Levy
- UCEDD UCLA Tarjan Center – Kecia Weller
- UCEDD USC - vacant

SSAN Officers

Cheryl Hewitt, Chairperson
Jennifer Allen, Vice Chair
Nicole Patterson, Secretary

2013-2014 SSAN Meetings

SSAN held 3 meetings between October 1, 2013 and September 30, 2014. Meetings were held on December 10 -11, 2013, June 23 - 24, 2014 and September 9 - 10, 2014. A meeting that was scheduled for March 2014 was cancelled due to budget issues.

Each SSAN meeting included member reports on issues and concerns in their regions, legislative updates, training for members, and resources to distribute to members' communities.

Members received legislative updates on these issues:

- Self-Determination
- Equity and Diversity
- Employment
- IHSS
- Autism Treatment Insurance Mandate
- Housing
- Abuse and Neglect
- Safety Plans for Licensed Facilities
- School Districts Suspending or Expelling Students

Members received training on:

- Social Security Work Incentives
- ASAN Pacific Alliance on Disability Self-Advocacy
- Goal Setting
- R-word
- Working Together
- Learning Disabilities
- Starting a Non Profit Organization
- Employment First
- Self Determination
- Leadership

During 2013-2014, SSAN worked on these organizational and operating issues:

- Developing a SSAN brochure,
- Revised bylaws,
- Elected officers,
- Compiling a listing of self advocacy groups throughout the state, and
- Established two committees

SSAN's committees on Employment and Self Determination were established to respond to community requests for trainings on these topics. The committees have developed outreach plans with timelines, and are developing training materials.

2013-2014 SSAN Accomplishments

What We Do

- *Develop the knowledge and skills to make a difference in our region and state.*
- *Speak up for people with disabilities.*
- *Learn about and advocate for issues important to people with disabilities.*
- *Lead regional and statewide advocacy groups and networks*

~SSAN Bylaws

Presentations & Trainings

SSAN members provided 64 presentations and trainings to 1180 individuals throughout the state. Presentation and training topics were:

- Medi-Cal Managed Care (17 participants)
- State Budget (2 presentations, 128 participants)
- SSAN (5 presentations, 260 participants)
- Transition (9 presentations, 380 participants)
- History of Rights (2 presentations, 12 participants)
- Employment First (2 presentations, 145 participants)
- Self Determination (36 presentations, 105 participants)
- Safety (12 participants)
- Self Advocacy (12 participants)
- Leadership (12 participants)
- Self Determination (12 participants)
- R –word (25 participants)
- Autism (20 participants)
- First Responders (40 participants)

Resource Sharing

SSAN members distributed information about these resources to their communities:

LOW COST GLASSES



The California Vision Project is a non-profit, optometric charity designed to provide low-income, uninsured families throughout the state of California with free comprehensive eye exams and low cost glasses. 1-800-877-5738
<http://www.californiavision.org/patients.html>

LOW COST INTERNET SERVICE



The Digital Access Project supports people with disabilities to get internet services at a lower cost, perfect for those who have limited incomes. <http://digitalaccessproject.org/>

SAFETY INFORMATION

**PREDATOR
AWARENESS
TASK FORCE**



The Predator Awareness Task Force (PATF) works to reduce the risk of victimization for people with developmental disabilities through education and advocacy
www.scoe.org/patf

WORK INCENTIVES

Disability Benefits 101
working with a disability in California



Learn how work and benefits go together. This site has tool and information on health coverage, benefits, and employment.
<http://ca.db101.org/>

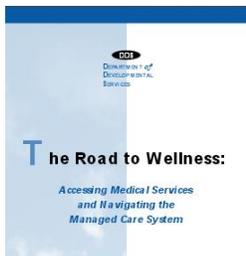
SUPPORT FOR SELF ADVOCACY GROUPS



ASAN is giving technical assistance to self advocates to help advocacy become stronger. ASAN will provide information about how to fundraise, find new members, and lead meetings. ASAN will help groups learn this by hosting trainings (via phone and computer) and mentoring groups.

<http://autisticadvocacy.org/chapters/padsa/>

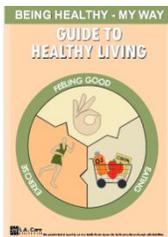
HEALTH CARE and WELLNESS



“The Road to Wellness: Accessing Medical Services and Navigating the Managed Care System” How to get Medical, what Medical covers, what to do if you have a problem.
<http://www.dds.ca.gov/Wellness/docs/medicaldirectorybklt.pdf>



Far Northern Regional Center’s Live Well. Internet Safety, Bed Bugs, Preventing Heat Illness, & more.
www.fnrclivewell.com



Guide to Healthy Living
http://www.dds.ca.gov/ConsumerCorner/docs/GuideHealthyLiving_English.pdf

Needs Assessment

SSAN members conducted surveys with self advocates in their local communities to determine training needs throughout the state. 236 surveys were completed. The results showed that self advocates wanted information about: 1. Good Health Care, 2. Work, and 3. Self Determination. See attachments for the SSAN survey and survey results.

Advocacy

SSAN members advocated in their regions on transportation, In Home Support Services, and housing.

Members distributed fact sheets and wrote letters to legislators on Employment First, Self Determination, SB577, AB 1595.

SSAN members provided testimony on AB 1041 – Employment First and SB 1109 - Integrated Competitive Employment.

Community Involvement

SSAN members were active in their communities and participated in a wide variety of community events, including:

- Capitol Action Day
- Support Life Conference
- People First of California Annual Gathering
- Regional conferences in Los Angeles, Tri Counties, North Bay, San Diego, and Region 6
- Autistic Self Advocacy Network Leadership Training
- Statewide Self Advocacy Conference
- Day of Remembrance
- National Core Indicators Training
- DO Network

“51.2 million people have some level of disability. Whereas, 32.5 million people have a severe disability. These numbers represent a significant portion of our population so the chances of our first responders coming into contact with them is great. That is why it is vital to have up to date training as well as assessment skills.”

Robert Balderama
Region 6 Member
Opening remarks, First Responder Training

Highlights of SSAN Members' Actions 2013-2014

Region 1 Willie West



- Suggested having a SSAN application process and piloted the SSAN recruitment documents in order to help build a stronger network.

Region 2 Charles Horne-Nutt



- SSAN surveys were collected 41 self advocates.
- A presentation was given to People First of Paradise about Medi-Cal Managed Care and the handout that was used in the training was shared with SSAN.
- Appointed to be a member of SCDD Area Board 2 by the Governor.

Region 3 Jennifer Allen



- Participated in Capitol Action Day
- Distributed SSAN surveys
- Attended ASAN Leadership training

Region 4 Michael Arbios



- Gave trainings on Employment First, History of Rights, Transition to Adult Services
- Facilitated regional meeting and gave presentation on state budget, introduced Assmelymember Mariko Yamada
- Distributed SSAN surveys

Region 5 Regina Woodliff



- Attended the People First Gathering in San Francisco
- Presented to transition students about the future.
- Presented to Concord City Council.

Region 6 Robert Balderama



- Self Advocacy Council 6 developed strategic plan and sponsored Area Meeting – 225 attended
- Presented at a training for self advocates, families and professionals regarding how First Responders interact with people who have disabilities
- Collected SSAN surveys from 128 self advocates
- SSAN reports are included in the Area Board 6 packet.
- As a member of the VMRC Board of Directors, shares SSAN info at their meetings. Has given out Employment First, Self Determination and AB1595 info

Region 7 Cheryl Hewitt



- Training provided on rights, choice, quality assurance, Lanterman Act for potential residential service providers.
- Connecting with Santa Cruz and regional center self-advocates.
- Self-determination will be a priority focus.
- Developed a Self Determination training package and completed seven trainings to 40 people, many in residential living.
- Participated in Disability Capitol Action Day and met with legislators
- Building a regional group of self advocacy organization

Region 8 Rebecca Donabed



- I gave a presentation on what the SSAN is to about 100-150 people.

Region 9 Sigrid Bremer



- Self Advocacy Conference was held.
- Sexual Rights DVD soon available from People First of San Luis Obispo.
- Attended the People First Gathering in San Francisco
- Spoke at the Tri-counties Town Hall Meeting.
- People's Advisory Group wrote a letter about the minimum wage change.

Region 10 Julie Gaona



- I keep working on transportation. We are trying to get other transportation companies to get involved in providing transportation.
- My husband and I gave our presentation at the self advocacy conference. We are both involved in the self advocacy board for Los Angeles county.

Region 11 Kyle Minnis



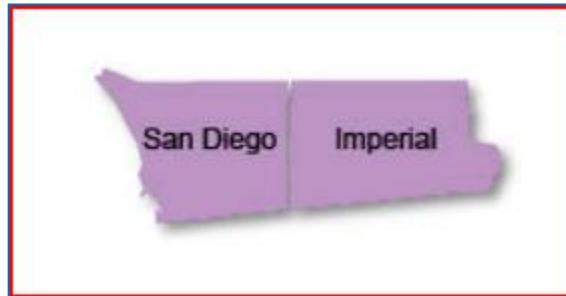
- Self-advocacy group hosted training for parents on the IPP process.
- Starting transportation advocacy for night hours.

Region 12 Chris Rogel



- Working on starting two new self advocacy groups.
- Giving presentations in Bishop, Ontario, Temecula and Blythe.
- I did presentations in a program called "Get Safe." It's a program about how to protect and provide safety.
- I presented what a self advocate does, how to become one, and what does self-advocacy mean. I also discussed that self advocates could make a difference to society.

Region 13 Trena Wade



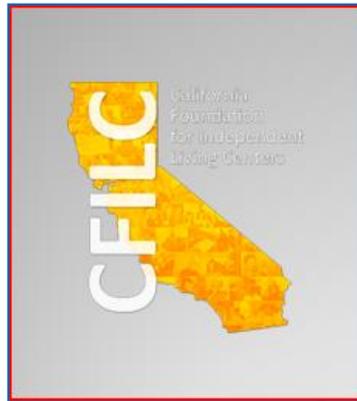
- Many ability awareness, cultural and advocacy events and presentations, including advocating with doctors, disaster preparedness, with the Native American community. Planning has started for San Diego People First (Mother's Day weekend) and Imperial County Conferences.
- Met with San Diego Regional Center on underserved populations

Association of Regional Center Agencies Jesse Padilla & Desiree Boykin



- Participated in Relationship Training
- Signature campaign to reinstate Early Start services
- Increasing the activity of self-advocates through Self Advocacy and Legislation work groups.
- ARCA Consumer Advisory Committee completed the SSAN survey.

California Foundation for Independent Living Centers Ted Jackson



- Organized 3 Access Now Power Summits where people with disabilities identified their advocacy priorities and developed community-driven campaign strategies to build accessible communities.
- The DOnetwork's Regional Access Now Campaigns have begun meeting and carrying out their campaign plans. They are working on transportation and healthcare in Southern California, getting more disability history in K-12th grade classrooms in the Central Valley and Northern California, and advocating for better accessibility on the new BART cars in the Bay Area.
- Organized the 12th Annual Disability Capitol Action Day (DCAD) on May 21, 2014 at the State Capitol. It was attended by nearly 1500 people with disabilities and their allies. Participants marched on the Solidarity March, heard speakers at the Educational Rally, got information and resources at the Disability Resource Fair and met with their legislators about important disability-related policy issues.

Department of Developmental Services Nicole Patterson



- Attended first Self Determination Stakeholder Advisory Group Meeting on how to organize the services.

Disability Rights California Daniel Meadows



- Legislative advocacy including passage of Self-determination and Employment First bills
- Starting Get Out the Vote campaign for Governor election 2014
- Partnering with the Office of Client Rights to better promote self-advocacy

People First of California Joe Meadours



- The Annual Gathering was held in San Francisco in February 2014.
- A book will soon be published: Board of Leaders: How to Be a People First Board Members.

State Council on Developmental Disabilities David Forderer



- New Committees developed: State Plan and Membership
- Committees –David is on Membership Committee
- Contract Purchasing manual completed
- Michael Clark has been appointed Interim Director

UCEDD MIND Institute Robert Levy



- I did a presentation about my Successes at the UCD MIND Institute for the Pathways to Employment conference
- Testified on SB1109 Integrated Competitive Employment bill.
- Passed out SSAN Training Module surveys at Disability Capitol Action Day
- Did a presentation with Ted Jackson at the Supported Life Conference about the SSAN and collected 28 SSAN Training Module surveys.
- 3 transition presentations on family preparation and work experiences at the 2014 Transition Fair at the Napa Valley College.
- Panel presentation on Living with Autism at UC Davis M.I.N.D.

UCEDD UCLA Tarjan Center

Kecia Weller



- FriendMaker App available on Itunes—based on Dr. Laugeson’s new book – The Science of Making Friends
- Inclusive Higher Education Conference in DC – the five year funding is ending; colleges are concerned about continuing the programs

UCEDD USC

vacant

SSAN Plans for the Future

For 2014-2015, SSAN officers identified these plans:

- **Communication** – Identify ways to facilitate members' communication between SSAN meetings with each other, and members' communication with their regions. One idea that is being explored is publishing a SSAN newsletter.
- **Legislative Advocacy** – SCDD has provided valuable legislative information and action alerts to SSAN. SSAN would like to engage in more legislative advocacy and expand the distribution of legislative information and alerts.
- **Continue to develop training** – SSAN is developing training materials about Employment First and Self Determination. SSAN would like to continually develop updated training materials. SSAN would like to contribute to the work of SCDD's Employment First Committee by providing trainings to self advocates about EFC's mission and accomplishments.
- **Networking** - Continue networking within SSAN, and network outside of SSAN with other agencies.

I want to do more to help change California so that everyone is treated with the same respect. I want to build up my strengths to pay things forward to be a voice to individuals that cannot speak up for themselves. Always remember that we can never do this alone, it always takes teamwork. Thanks for allowing me to be part of a positive and productive team that is going to help plan for changes in California for individuals with disabilities.

Charles Horne-Nutt
Region 2 Member

Attachments

SSAN Training Survey

SSAN Training Survey Results



Statewide Self-Advocacy Network (SSAN)



Training Module Idea Survey

The State Council Self-Advocacy Grant Contractor CAPC will work with SSAN to develop 4 Train the Trainer Modules. At our March meeting we will select the topics.

To help with this discussion, please get input from your area network on which modules will help people the most. Please fill out as many of these surveys as you can before March 17. The form can be filled out by individuals or group.

Contact Sherry Beamer if any questions and to return your results:

beamers@capcinc.org

562-652-1759

7200 Greenleaf Ave Suite 170, Whittier, CA 90602

Choose 4 Ideas:

Work

Self Determination

Starting Self-Advocacy Groups

Good health care

Good life for seniors

Other: _____



If you chose Work, pick at least 1 topic:

- Writing a resume
- How to sell yourself to get a job
- How to build your job skills
- How to learn about and find jobs that are right for you
- Other: _____



If you chose Self Determination, pick at least 1 topic:

- What is it?
- How does it work?
- How can I be part of it?
- Why is it good?
- When is it not easy?
- Success stories
- Other: _____



If you chose Starting Self Advocacy Groups, pick at least 1 topic:

___ How to start self-advocacy groups

___ How to create a statewide advocacy plan

___ How to build community partnerships

___ How to teach new leaders

___ Other: _____



If you chose Good Health Care, pick at least 1 topic:

___ How does the Affordable Care Act affect us?

___ How does Medi-cal work?

___ How to find the best doctors?

___ Other: _____



If you chose a Good Life for Seniors, pick at least 1 topic:

___ How do I retire?

___ How do I plan for the end of my life?

___ How do I get different supports as I get older?

___ Other _____



If you chose another idea, list at least 1 topic:



Training Module Idea Survey

RESULTS

Choose 4 Ideas:

104 Work	2 nd Place
88 Self Determination	3 rd Place
77 Starting Self-Advocacy Groups	4 th Place
105 Good health care	1 st Place
69 Good life for seniors	
10 Other: _____	

OTHER: Comments

- Educating California Students about developmental disabilities and human rights!
- Better hygiene care
- Internet Training
- Exercise
- Be Independent



If you chose Work, pick at least 1 topic:

24 Writing a resume

25 How to sell yourself to get a job

25 How to build your job skills

53 How to learn about and find jobs that are right for you

4 Other: Comments- To get along at the job
How to learn the job



If you chose Self Determination, pick at least 1 topic:

27 *What is it?*

28 *How does it work?*

20 *How can I be part of it?*

14 *Why is it good?*

10 *When is it not easy?*

24 Success stories

2 Other: Comments- How to avoid being taken advantage of
How to motivate people to be interested in SD



If you chose Starting Self Advocacy Groups, pick at least 1 topic:

- 39** How to start self-advocacy groups
- 23** How to create a statewide advocacy plan
- 20** How to build community partnerships
- 23** How to teach new leaders
- 4** Other: Comment- How to keep self-advocacy groups running



If you chose Good Health Care, pick at least 1 topic:

- 38** How does the Affordable Care Act affect us?
- 34** How does Medi-cal work?
- 46** How to find the best doctors?
- 7** Other: Comments:
 - How to balance my diet to keep my weight down
 - How to find the Best doctors
 - Teaching good habits so you take care of yourself
 - Offer Healthier foods & snacks at programs
 - No junk food!



If you chose a Good Life for Seniors, pick at least 1 topic:

- 21** How do I retire?
- 20** How do I plan for the end of my life?
- 43** How do I get different supports as I get older?
- 4** Other: Comment- Network



If you chose another idea, list at least 1 topic:

- We have a very small population that has a full understanding of the disability movement and people with developmental disabilities. If we educate our youth, throughout their elementary, middle school, and high school years about developmental disabilities we will have much less bullying and more opportunities for self-determination, education, work and housing.
- Be more independent and living on my own
- Draw pictures
- How to use the internet
- Public speaking