

Statewide Self-Advocacy Network





Thank you to members of the State Council and Area Boards on Developmental Disabilities for their commitment to advocacy lead by Californians with disabilities. This booklet describes how the Statewide Advocacy Network will ensure self and peer advocates lead by example to impact change.

Carol Risley, Executive Director

## **Mission Statement**

State Council on Developmental Disabilities (SCDD) is established by state and federal law as an independent state agency to ensure that people with developmental disabilities and their families receive the services and supports they need.

# **Acknowledgements**

State Council on Developmental Disabilities State Council Self-Advocates Advisory Committee Area Boards on Developmental Disabilities

## **Booklet contributors:**



Jennifer Allen



Molly Kennedy



Robert Taylor



Lisa Cooley



Jimmy Lee







The California State Council on Developmental Disabilities advocates, promotes and implements policies and practices that achieve self-determination, independence, productivity and inclusion in all aspects of community life for Californians with developmental disabilities and their families.



The Statewide Self-Advocacy Network will build an alliance of self-advocates that links California communities with statewide organizations to advance civic participation and advocacy by persons with disabilities.



This booklet describes construction of a vibrant statewide system of advocacy that enables interchange, practical learning and leadership across the state.



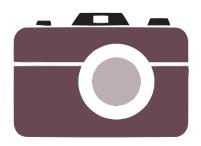
# **Table of Contents**

	Statewide Self-Advocacy Network
	Introduction
	Purpose9–11
	Background13–15
Please	Statewide Partnerships
	How It Works17–21
	Support
S 2 2 2 1	Outcomes & Evaluation
	Resources



# Statewide Self-Advocacy Network

# **Snapshot**



The Network is a newly created framework that will unify, centralize and strengthen the efforts of existing advocacy groups that operate in the State of California.

Each of the 13 regions and identified statewide advocacy organizations will select a representative to participate in quarterly leadership trainings and meetings. Representatives will bring current and long-term advocacy interests and goals to the statewide meetings. Network members will provide progress reports on community-based projects. Multi-year outcome driven plans will be established and tracked.

The Council will maintain Network web pages on its website where each region will have opportunities to highlight advocacy activities. Information sharing will be encouraged. Self-advocates, families and the community will have access to materials, tools, and presentations.

The Council will provide funding for facilitation support to assist the Network with leadership and organizational development. Network materials and tools will be provided in understandable formats and available through the Council's website.

The Network will join self-advocacy efforts across communities and move advocacy by persons with disabilities to the forefront in California.



## Introduction

# **Molly Kennedy**



Who should be leading the advocacy movement? Individuals with disabilities want to be treated with respect and be in charge of their lives so it begins with their voices leading. To earn true equality, we have to advocate for ourselves and not let others, though well meaning, determine our course.

Everyone with developmental disabilities needs to see themselves as an advocate. Understand what it takes to be an advocate and how to build these skills. Each individual should advocate not only for their own needs, but for system changes that benefit everyone



## Introduction

Established by state and federal law to ensure people with developmental disabilities and their families receive the services they need, State Councils on Developmental Disabilities are funded by the federal Administration on Developmental Disabilities (ADD). Every State Council develops a five-year state plan and implements activities designed to improve the availability and quality of services for persons with developmental disabilities. To accomplish their objectives, State Councils utilize strategies such as training, building coalitions, educating policymakers, barrier elimination and funding projects that address priority areas.



The California State Council on Developmental Disabilities (Council) is unique in having a network of 13 regional offices, known as Area Boards on Developmental Disabilities, leading community-based activities. Because of the size, complexity, and diversity of California, it is critical to include local communities in both the development and implementation of the State Plan. Through area boards, the Council assists

with advocacy, training, coordination, and achievement of State Plan goals. Regional and statewide outcomes are reported to the California legislature and federal government.



## Introduction

Central to accomplishment of the Council's mission is an active commitment to leadership by persons with disabilities in personal and public advocacy. By supporting the development of the Statewide Self-Advocacy Network—**Network**—with strong local roots and effective regional representation, the Council seeks to strengthen pathways to change led by persons with disabilities.



## **State Council's goal #1:**

"Individuals with developmental disabilities have the information, skills, opportunities and support to advocate for their rights and services and to achieve self determination, independence, productivity, integration and inclusion in all facets of community life."

The complete State Plan is located on the Council's website at



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



# **Lisa Cooley**



I want to create a world where the word "inclusion" is not just a concept for people who have developmental disabilities. For too many decades, people with all kinds of disabilities – but specifically developmental disabilities – have been on the fringes of life and not really fully included.

Call it tokenism, if you must. We have only been included because it is the legally appropriate thing to do, or it's the feel good thing. I want not only our state, but the world, to do better than that.





Human rights apply to all persons and carry a pledge of equal opportunities to life and liberty. The Convention on the Rights of Persons with Disabilities (CRPD), the first human rights treaty of the 21st century, strengthens obligations that ensure persons with disabilities are included in society and supported to build their capacities. The belief underlying self and peer advocacy is that informed decision-making and civic engagement promote environments where persons with disabilities can enjoy real equality.

The Network assists individuals who rely on California's human service systems to direct efforts that result in more Californians with disabilities exercising fundamental freedoms.



For more information on the treaty go to http://www.un.org/disabilities/

To view CRPD videos go to http://brcenter.org/lib/SP\_TR\_CRPD.php



For decades, local, regional and statewide self-advocacy organizations have worked to improve the quality of life and protect the rights of Californians with disabilities. By uniting these efforts, the Network will lessen fragmentation and increase the impact of





The Network addresses evolving local and statewide advocacy interests with practical approaches that reflect the needs of the people they represent. Plans are outcome-driven with activities and accomplishments reported to the Council, legislature and federal government.



The Council is committed to supporting self-advocates to build the Network so together they may expand:

## Personal leadership

Choosing a direction in life and taking action.

## Civic Engagement

Working to make a difference in the community and developing the knowledge and skills to make that difference. Promoting quality of life in a community through political and non-political processes.

## ■ Peer Representation

Speaking or acting on behalf of other people with disabilities.

## Advocacy

The political process of influencing public policy to advance the interests of people with disabilities.



# Background

## **Jennifer Allen**



I believe the self-advocacy network would be an important tool for all persons with disabilities in California. It will bring together self-advocates and organizations around the table to create a new avenue in the advocacy community.

The network will expand on the methods that have been used up until now. We already have some things in place, but now more information and tools will be available.



# Background



In 2011, the Administration on Developmental Disabilities (ADD) convened a Self-Advocacy Summit in Los Angeles to solicit state and national recommendations for strengthening self-advocacy across the country. The California team (self-

advocates representing the Council, Disability Rights California, People First of California, and University Centers for Excellence in Developmental Disabilities) recommendations focused on:

- Statewide Network
- Area Boards to support self-advocacy outcomes in communities
- Statewide coalition building and peer-led participation
- Statewide self-advocacy resource library

Suggestions by the California team also reflected national recommendations:

- 1) ADD Consumer Advisory Committee or national task force
- 2) user-friendly websites for self-advocacy information
- 3) more influence in public policy
- 4) disability awareness
- 5) outreach to youth and underserved communities



# Background

Building on the ADD Summit recommendations and California's self-advocacy accomplishments, the Council called for invigorated collaboration among local, regional and statewide organizations to carry out the State Plan.

#### **Goal #1:**

Individuals with developmental disabilities have the information, skills, opportunities and support to advocate for their rights and services and to achieve self determination, independence, productivity, integration and inclusion in all facets of community life.

- Promote stability and expansion of a statewide self-advocacy network, ensuring local delegates participate effectively in statewide meetings and events.
- 2. Strengthen existing self-advocacy groups and promote establishment of new groups at the local level.
- 3. Help to educate self-advocates so they are better able to assert their human, service and civil rights, prevent abuse, neglect, sexual and financial exploitation and be better informed.
- 4. Collaborate with local and statewide groups to promote and support the efforts of cross-disability and youth disability organizations to expand and strengthen their leadership network.
- 5. Support and train self-advocates to become effective trainers and facilitators.



# Statewide Partnerships

Accomplishing meaningful advocacy—personal, peer or public policy—requires partnerships. The responsibilities of Network members will foster a collaboration of shared information and action. Invited partners include:



Association of Regional Center Agencies



California Foundation for Independent Living Centers



Department of Developmental Services



Disability Rights California



People First of California



State Council on Developmental Disabilities

Universit y Centers for Excellence in Developmental Disabilities



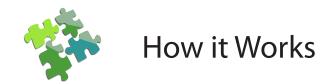
**UCLA** 



USC



**UC DAVIS** 



# Robert M. Taylor

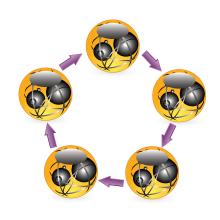


For peer and self advocates to point the way, for groups and organizations to be successful, they have to be leaders in the decision-making. If you are a leader that sets the example, people will follow your lead, and when you do it, things come out good for you!

When you are a leader, it is a great learning experience. Good leaders who belong to groups and organizations, know how to get things done, and can succeed.



## **How it Works**



## **Structure**

The Network promotes advocacy linkages among community, regional and statewide leaders:

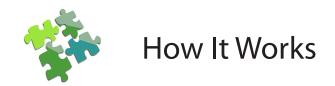
- One representative from each statewide organization
- One representative from each of 13 area board regions

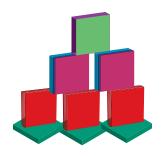
### Organizational Responsibilities

- Provide facilitation to Network members to carry out activities
- Assist communication between the Network and advocacy groups
- Help create statewide and regional advocacy plans
- Support advocacy plan activities

## Network Member Responsibilities

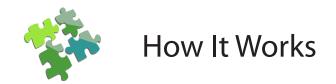
- Attend quarterly meetings
- Collaborate to create statewide and regional advocacy plans
- Carry out advocacy activities with local, regional and statewide organizations
- Collect information and contribute to Network reports
- Utilize and share strategies and tools





# **Network Strategies**

- 1. Statewide meetings to focus on core leadership areas and advocacy interests identified by members.
- 2. Think-Plan-Do decision-making process to learn and lead by example.
- 3. Community building through local and statewide advocacy planning and implementation.
- 4. Resource exchange through Network web pages on Council's website where members and regions highlight tools and activities.
- 5. Accessible formats, plain language and multi-media tools.
- 6. Annual reporting about Network activity and outcomes.
- 7. Utilization of communication technologies.



## **Coordination**



The Network meets quarterly over two days for leadership training, sharing expertise, planning and reporting on progress.

- Training to learn and practice leadership skills to share in communities. Members initiate personal and peer leadership goals that lead to community and statewide advocacy outcomes.
- Creating and following up on advocacy plans and assignments.
  Members share experiences and report on activities.
- Prioritizing statewide activities for policy making and systemwide advocacy.

# How it Works

As a leader, it is important to understand firsthand the meaning of self-determination and how to exercise basic rights to a better quality of life. To gain practical experience in leadership, Network members determine their own personal and professional advocacy goals and carry out plans. Steering the statewide advocacy Network, members promote teamwork and expand expertise.

## Leading by example means:

- Demonstrating personal change that others may follow
- Sharing learning experiences and teaching tools
- Advocating for the rights of others, not only for oneself
- Reaching out to others and respecting differences

Drawing on their own experiences, Network members increase their skills as community and statewide leaders. With increased engagement in their communities, individuals with disabilities take the lead to:

- Link self and peer advocacy efforts across the state
- Advocate with local, state and national policy-makers
- Impact local, state and national policies



# Support

The Council supports Network meetings quarterly and provides:

- Travel related costs
- Meeting facilitation and leadership training
- Self-Advocacy Resource Room
- Network web pages and additional online resources
- Network leadership materials for community use
- Guidance and training materials for facilitators to support network members
- Follow through with plan development, implementation and reporting
- Network materials and tools designed in accessible formats



# **Outcomes & Evaluation**

**Jimmy Lee** 



The time has come for the outside world to recognize us as human beings. For too long, we have been treated as trouble makers, a burden, scapegoats, outcasts and rejects. I will make the unheard voices be heard.

I will speak loud and clear for those who can't.



## **Outcomes & Evaluation**

## **Outcomes**

- 1. Network members expand:
  - Personal leadership accomplishments
  - Civic engagement
  - Peer representation
  - Advocacy and statewide leadership
- 2. Network establishes stable membership and operating rules, with regular participation by members in community and statewide advocacy.
- 3. Network demonstrates use of multi-media and accessible formats for complex information, available to Network members, advocacy groups and the general community.
- 4. Increased Network influence in public policy making and presence.



# **Outcomes & Evaluation**

## **Evaluation**



1. Network member progress reports on leadership.



2. Annual Network Summit to review progress, accomplishments, effective strategies and areas for advancement.



3. Annual Network report to Council, in booklet and video formats.



## Resources

The Council is developing a sustainable advocacy resource center that provides online and published resources to support self and peer advocacy across California. Self-advocates, families and the general community are encouraged to access all materials, tools and presentations.

#### Website

- Statewide Self-Advocacy Network web pages Activities, materials and reports with highlights of local and regional advocacy activities
- Statewide advocacy and leadership resource center

## **Council Advocacy Resource Room**

1507 21st Street, Suite 210 Sacramento, CA 95811

#### **Right of Use**

Council resources are available and may be downloaded, copied, distributed and transmitted under the following conditions:

- ♦ Attribution Attribute the work to the California State Council on Developmental Disabilities (but not in any way that suggests the Council endorses your use of the work).
- ♦ *No Derivative Works* Do not alter any materials.
- ♦ *Noncommercial* Do not use any materials for commercial purposes.