CALIFORNIA YOUTH LEADERSHIP FORUM YLF For Students With Disabilities

July 22-26, 2013

"BE THE CHANGE"



Student Delegate Workbook and Schedule

Name:

ORIGINALLY DEVELOPED BY THE CALIFORNIA GOVERNOR'S COMMITTEE ON EMPLOYMENT OF PEOPLE WITH DISABILITIES

	Week At A Glance - YLF 2013						
	Sunday 7/21	Monday 7/22	Tuesday 7/23	Wednesday 7/24	Thursday 7/25	Friday 7/26	
Theme:	Move In	Introducing Ourselves and	Disability Community,	Discovering Resources to	Getting Involved with the	Now We Begin the Rest of	
		YLF Breakfast	Culture & History Breakfast	Reach my Goals Breakfast	Community Breakfast	Our Lives Breakfast	
7:00 AM	Set up	(7:00-8:00)	(7:00-8:30)	(7:00-8:30)	(6:45-7:45)	(7:30-8:30)	
7.007.001	corup	Dining Hall	Dorm	Dorm	Dorm	Dorm	
8:00 AM		Free Time	Small Groups (8:45-9:15)	Small Group (8:45-9:15)	Travel to State Capitol (8:00)		
9:00 AM		Staff Breakout Sessions (9:00-9:30) Small Groups Planning Session (9:30-11:00) Delegates Arrive Box Lunches Check-In and Bingo (11:00-2:00) Small Groups (2:00-3:00)	Large Group YLF Extreme Games (9:30-11:00)	Large Group Assistive Technology and Resource Fair (9:30-10:45)	Photo Session and Activities on Capitol Steps (8:45-9:45)	Small Groups (8:45-10:30)	
10:00 AM					Governor's Office: How to Be an Effective Change Agent (10:00-10:45)	Closing Session: Take it Back to Your Community!	
11:00 AM			Large Group Disability History and Culture (11:15-12:00)	Visit Campus Bookstore in Small Groups (11:00-12:00)	Legislative Visits (11:00-11:45)	(10:45-12:15)	
12:00 PM	Box Lunches for staff that arrive earlier than the 2 pm orientation		Lunch (12:00-1:00)	Lunch on Campus (12:00-1:15) Student Union Food Court	YLF Luncheon (12:15-2:30) Convention Center	Box Lunch Served (12:30) Eat on site or take with you Final Checkout Activities	
1:00 PM			Large Group Disability Etiquette Skits (1:15-2:15) Arts Performance (2:15-3:00)	Voting and Legislative Advocacy Presentation (1:30 - 2:00) Living on my own and reaching my career goals: Panel presentation (2-3:30)		Buses Load (1:30) Buses Depart (2:00)	
2:00 PM	Staff Arrive (2:00-3:00)					Dorms to be cleaned and vacated (2:30)	
3:00 PM		Large Group: Opening Session (3:15-5:15) Dinner in Small Groups (5:30-6:30)	Small Groups (3:15-4:45)	Small Groups (3:45-4:45)	Capitol Tours (3:00-4:00)		
4:00 PM	Staff Orientation (3:00-6:00)				Return to CSUS (4:00)		
5:00 PM			Dinner (5:00-6:00) BBQ by Pool and Band	Dinner (5:00-6:00) Dining Hall	Dinner (5:00-6:00) Dining Hall		
6:00 PM	Staff Dinner in Dorm (6:00-7:00)	Small Groups (6:45-8:00) Free Time /Staff Meeting (8:15-9:00)	Alumni Sharing (6:15-8:30)	Small Group (6:15-7:15)	Small Group (6:15-7:15) Dance (7:30-10:00)		
7:00 PM	Staff Orientation, Cont. (7:00-7:30)			Talent Show (7:30-9:00)			
8:00 PM			Delegates Prepare for Talent Show/Staff Meeting (8:30-9:00)				
9:00 PM		Free Time	Free Time	Free Time/Staff Meeting	(1.00-10.00)		
10:00 PM		Lights Out (10:00)	Lights Out (10:00)	Lights Out (10:00)	Lights Out (10:30)/Staff Meeting		

WORKBOOK TABLE OF CONTEN	TS
INTRODUCTORY INFORMATION	1
Purpose of the Youth Leadership Forum	2
Ground Rules and Guidelines	3
Circle Square Triangle Hexagon: Debrief Activity	6
DAY ONE (MONDAY)	11
The Ungame	12
Alike and Different	13
Rules to Meet By	14
Golden Tickets, E-O-Grams, and Power Tree	15
Presenter Introductions	17
Disability Etiquette Skits	19
Circle Square Triangle Hexagon: Debrief Activity	22
DAY TWO (TUESDAY)	23
Qualities of a Leader	25
Talking About Disability Activity	26
 Social and Medical Models of Disability 	27
Fill in the Blanks	28
Leadership Compass	29
Circle Square Triangle Hexagon: Debrief Activity	33
DAY THREE (WEDNESDAY)	35
Create it, Believe it, Achieve it! Activity	37
Circle Square Triangle Hexagon: Debrief Activity	45
DAY FOUR (THURSDAY)	47
Circle Square Triangle Hexagon: Debrief Activity	50
DAY FIVE (FRIDAY)	51
Sample Letter to Myself	
Sample Letter to Donors	
What People Like and Admire about Me	55
PERSONAL LEADERSHIP AND ADVOCACY PLAN	
TOOL BOX OF ADDITIONAL INFORMATION	
Transition Toolkit Flyer "In One and of Dischilts Qualtume" Article	63
"In Search of Disability Culture" Article Disability Logders	
Disability Leaders	74
 Quotes	77 78
	78 79
 YLF Alumni	79 80
	00

INTRODUCTORY INFORMATION

Purpose of the Youth Leadership Forum

Ground Rules and Guidelines

Circle Square Triangle Hexagon (Debrief Activity)

PURPOSE OF THE YOUTH LEADERSHIP FORUM

WHAT WILL WE ACCOMPLISH THIS WEEK?

We will share many experiences this week involving the principles of leadership. Our activities will show us ways to reach our personal and career goals by helping us to develop an appreciation of the past, an understanding of the present and a belief in the future.

During the Forum, we will:

YLF GOAL 1 "Develop an Appreciation of the Past"

• Learn about the history and experiences of people with disabilities and understand why there is a "disability culture."

YLF GOAL 2 "Develop an Understanding of the Present"

- Explore the basic principles that make a leader.
- Meet with people with disabilities who are successful personally and professionally.
- Participate in new experiences to help us learn and reach our goals.

YLF GOAL 3 "Develop a Belief in the Future"

- Learn about career and education options.
- Learn about resources to reach our goals.
- Learn ways to make positive contributions to the community.
- Develop a "Personal Leadership and Career Plan" to use when we return home to help us reach our goals .

EACH DAY DURING YLF HAS A THEME:

MONDAY: Introducing Ourselves and YLF.

TUESDAY: Disability History, Culture and Community.

- **WEDNESDAY:** Discovering Resources to Reach Our Goals.
 - THURSDAY:: Getting Involved in the Community.

FRIDAY: Now We Begin the Rest of Our Lives.

GROUND RULES AND GUIDELINES FOR DELEGATES AND STAFF

You have been selected to attend this forum because of your leadership potential. These basic ground rules and guidelines will help make sure YLF is a great experience for everyone.

Please note: Any serious violations of these rules will result in students being sent home <u>immediately</u> at parents'/guardians' expense. And most importantly, remember that it is an honor for you to have been chosen to attend YLF—so have a great time!

ALL DELEGATES AND STAFF MUST:

- Maintain a respectful attitude toward peers, facilitators and conference staff.
- Respect the facilities, including maintaining the condition of dormitory rooms and all other areas. Participants will have to pay for property damage they cause and for lost room keys or towels.
- Interact with as many students as possible during the forum.
- Be where you need to be, when you need to be there. Attendance at all sessions is mandatory including ALL meals and social functions.
- Stay with your assigned Small Group at all times. (Supervision is mandatory for all participants.)
- Be out of dorms by 7:30 a.m. at the latest. (Wake-up call is at 6 a.m. and breakfast is served from 7 a.m. 8:30 a.m.)
- Be in your room each night for lights out at (most nights at 10:00 p.m.)
- No cell phones, text messaging, stereos, radios or electronic games permitted during forum sessions. They can only be used in dorm guestrooms before 7 a.m. and after 9 p.m.
- After arrival on campus, no student delegates are allowed to drive or ride in personal vehicles belonging to student delegates (until departure).
- All Sacramento State University facilities and other residence halls are off limits to delegates except for our headquarters, Desmond Residence Hall, or when used with staff supervision as part of the YLF program.
- If you have any problems or questions, please contact one of your group co-counselors.
- When not in assigned groups, delegates are restricted to their own assigned rooms at all times. No coed visitation is allowed in guestrooms.
- Use of the swimming pool is prohibited by Sacramento State University.

- Smoking, possession or use of illegal chemicals or alcohol is strictly prohibited.
- Possession and use of prescription or other approved medications is permitted only with written permission/instruction slip on file from parent/guardian or physician. Nursing staff in first aid station will dispense medication.

Guidelines for Small Group Discussions:

A major purpose of group discussions is to learn from fellow participants and likewise teach fellow participants by sharing your experiences, ideas and feelings. Here are some principles to keep in mind:

- Respect for People Give full attention to the person who has the floor (permission to speak). Let people speak one at a time and do not interrupt.
- Confidentiality What we share in this group will remain in this group.
- Openness No individuals should feel pressured to contribute or speak, but everyone benefits when everyone participates. We will be as open and honest as possible without disclosing other people's private issues.
- Right to pass It is always okay to pass (meaning "I'd rather not answer").
- Nonjudgmental We can disagree with someone's point of view without putting that person down. Try not to make judgmental statements such as "You shouldn't" or absolute statements such as "You never" or "I always."
- Making "I" statements Beginning your sentence with "I" helps you take responsibility for your statement. (For example, instead of saying, "You don't need to live alone to be independent," say "I don't think you need to live alone to be independent".)
- Listening Listening is as important as speaking -- both are important ways of contributing to discussions.
- Sensitivity to diversity Remember that people in the group may differ in cultural background, disability, sexual orientation, and/or gender identity or gender expression and be careful about making insensitive remarks.
- Anonymity It is okay to ask any question by writing it down.
- Acceptance It is okay to feel uncomfortable; adults feel uncomfortable, too, when they talk about sensitive and personal topics.
- Have a good time It is okay to have a good time. Creating a safe space is about coming together as a community, being mutually supportive, and enjoying each other's qualities.

- Equality The Co-Counselors and other staff are facilitators but are not in charge of the discussions and they do not have the right answers. The group discussion is a democratic process, and all participants are equal.
- Expression Words are not the only way to communicate. Be aware of how you communicate with body language, facial expressions and voice tone.
- Change We all interpret statements made by others and events that happen but we all can change how we interpret things.

Adapted from Advocates for Youth, © 2002 Washington, DC.

CIRCLE SQUARE TRIANGLE HEXAGON: DEBRIEFING ACTIVITY

Every day this week, you will complete the following activity at the end of the day. You will be asked to think about the questions below, and then you will be able to share your responses if you'd like.

Think about what happened during your day at YLF, and try to answer at least one of the following questions. Don't feel bad if you don't have an answer for any of these.

CIRCLE - What is one question going around in your head?

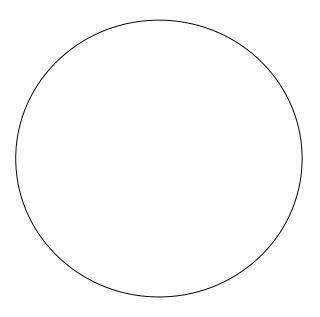
SQUARE - What is one idea or concept you heard today that "squares" or agrees with something you already think?

TRIANGLE - What are 3 important points for you to remember after today?

HEXAGON-What is a difficult idea you've been faced with today, or something you're having a hard time being comfortable with?

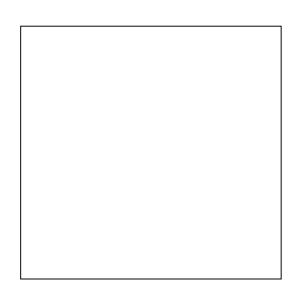
DEBRIEF ACTIVITY Circle, Square, Triangle, and Hexagon

CIRCLE: A question going around in my mind...

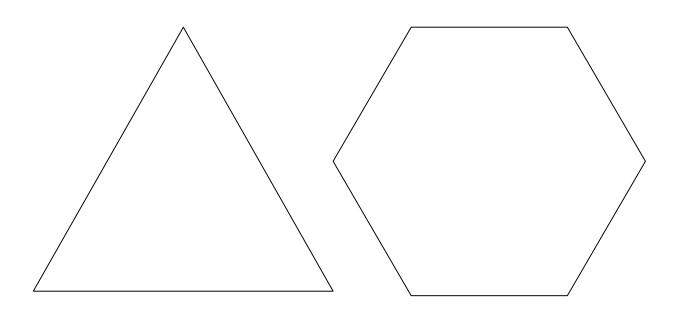


TRIANGLE: Three important points to remember...

SQUARE: Something that squares with my beliefs...



HEXAGON: An idea I'm having a hard time being comfortable with...



DAILY SCHEDULES

DAILY PROGRAM SCHEDULE MONDAY, JULY 22, 2013

DAILY THEME: Introducing Ourselves and YLF

11:00 a.m. – 2:00 p.m.STUDENT DELEGATE CHECK-IN Desmond Hall Large Room

- o Delegates check in and take photos
- o Play BINGO game

2:00 p.m. – 3:00 p.m. STUDENT ORIENTATION IN SMALL GROUPS Desmond Hall Small Meeting Rooms

- o Introduction of delegates and small group staff
- o Discuss and develop Ground Rules
- o Select group name
- o Information on Presenters Introduction

3:15 p.m. – 5:15 p.m. LARGE GROUP Desmond Hall Large Room

- o Introductions and welcoming remarks
- Presentation by YLF Alum
- Keynote Presentation by Jessica Cox

5:30 p.m. – 6:30 p.m. DINNER

Residence Dining Hall

- Delegates meet outside Desmond Hall and go together to Residence Dining Hall in assigned small groups with staff
- 6:45 p.m. 8:00 p.m. SMALL GROUPS Desmond Hall Small Meeting Rooms
- 8:15 p.m. 9:00 p.m. PREPARE FOR TALENT SHOW& FREE TIME FOR DELEGATES/STAFF MEETING Desmond Hall
- 10:00 p.m. LIGHTS OUT

THE UNGAME (Monday)

DIRECTIONS: Sit in a circle and have the first person pick a number from 1 to 10. He or she then must answer the question they picked. Continue around the group until everyone has answered at least one question. (Student delegates and staff participate.)

- 1. If you could have been anyone in history, who would you have been and why?
- 2. If you received \$5,000 as a gift how would you spend it?
- 3. What is your favorite sport and why do you like it?
- 4. If you become President of the United States, what two things would you do?
- 5. What kind of animal are you most like, and why?
- 6. Share three things for which you are thankful.
- 7. What is one of your hobbies?
- 8. What is something you can do well?
- 9. If you had to move and could only take three things with you, what would they be?
- 10. If you could take only three people with you on a trip around the world, whom would you take?

ALIKE AND DIFFERENT (Monday)

_

ALIKE

Come up with a list of what you have in common:

DIFFERENT

Now come up with a list of your differences:

_

RULES TO MEET BY (Monday)

High Expectations

What are high expectations? The connection between what the outside world thinks that you're capable of and what you really are able to do is a powerful one. A lot of times people think that if you have a disability, if you belong to a different racial or ethnic group, what kind of neighborhood you come from, or how old (or young) you are that you aren't able to do as well as someone else. Sometimes folks think that they need to protect you, or take care of you, or maybe even feel sorry for you. THAT IS NOT THE CASE HERE! YLF is founded on the idea of <u>high expectations for all</u>! This relates to what we think you're capable of, the conduct we expect from you, and the conduct you should expect from each other.

Before we get into the more concrete safety related do's and don'ts, let's take a few moments to come up with some "rules to meet by." Come up with five things that would make you feel like you could participate best at YLF. This could include how you want to be treated, how to best use your time, and what makes you more comfortable speaking up or sharing in a group.

Rules to Meet By

1.	, , , , , , , , , , , , , , , , , , ,
2.	
3.	
4.	
5.	

Adapted from Advocates for Youth, © 2002 Washington, DC.

WAYS TO GIVE OR GET APPRECIATION DURING YLF (Monday)

"YLF Golden Tickets":

- You have the opportunity to earn tickets by demonstrating leadership qualities, including (but not limited to): helping out other delegates or staff, speaking up during small or large group discussion, solving problems, general cooperation, and following the "golden rule" (treating others as you would like to be treated).
- Once you get a ticket from YLF staff, you should write your name and group number on the ticket and place it into the bucket at the front desk.
- Throughout the week, drawings will be held for various prizes.

"E-O-Grams" (Encourage-o-grams):

- It's helpful to tell someone when you appreciate something they say or do.
- To write an E-O-Gram to another delegate or staff member, there are pieces of paper available in the box in your small group room, and in the hanging folders by the front desk.
- If you don't feel like saying it directly, you can leave them a message in the E-O-Gram folder by the front desk. Each Small Group has a folder, and the Peer Counselors are responsible for handing out all messages.

"Power Tree": The concept of this activity is that you have the opportunity to anonymously share your experience(s) of an "-ism" that you have come across directly or indirectly, as a person with a disability. Some of these "-ism's" are racism, sexism, classism, ableism, ageism, etc. These are experiences where you have been treated differently because of your disability, your age, your ethnicity, your gender, your sexual orientation, or anything else about your identity as a person. Write those experiences on the leafs provided and your peer counselor will place them on the Power Tree in the large room. There you will also be able to view your peers' experiences of "-ism's."

This experience can be related to your disability, bullying experiences, life challenges, or everyday struggles. Most importantly...these are completely anonymous!!

This activity also empowers the readers' of the Power Tree to confess their feelings, dreams, stories, experiences, and ideas that otherwise would not be shared.

You can personalize the front of the leaf, or just share your secret on a pre-made leaf provided.

We experience these "-ism's" almost daily. Think hard. The sky is the limit!

INFORMATION ON PRESENTER INTRODUCTIONS

(Monday)

Introducing the YLF Presenters

Delegates from each small group will introduce and thank speakers throughout the week.

Instructions:

- Volunteer in your small group to either introduce or thank a speaker.
- If you are going to introduce a speaker, you will interview the speaker ahead of time. Pick 2-3 questions below to interview the speaker (or make up questions of your own). When asked, take the microphone and introduce the speaker, using their responses to your interview questions to tell the group about who they are.
 - What's your name and where are you from?
 - What do you do for work?
 - What are your hobbies/favorite thing(s) to do?
 - Who has been your biggest mentor/role model?
 - If you could eat only one food for the rest of your life, what would it be?
- If you are going to thank a speaker, go up after the person is done speaking, take the microphone, thank the person on behalf of YLF, and present them with a gift (which the YLF staff will give you).
- Practice ahead of time!

Here is a list of what time slot each group will handle, with names below of the people they will introduce.

Alumni Staff (demonstration): Monday night Opening Session

- YLF Alum (to be determined)
- Jessica Cox

Group 1: Tuesday Morning

Disability History & Culture Presentation:

• Vivian Wong

Group 2: Tuesday afternoon

Disability Arts Performance:

• Mark Goffeney

Group 3: Wednesday afternoon

Living On My Own and Reaching My Career Goals:

• Panel Members

Group 4: Thursday morning

Governor's Office:

- Sarah Triano, YLF Alumna
- Governor's Office Representative (to be announced)

Group 5: Thursday afternoon

Luncheon:

- Bobby McMullen
- Dani Duran, YLF Alumna

Disability Etiquette Skits (Monday)

Disability Etiquette Skits activity: Take the next <u>30 minutes</u> to develop a 5 minute skit with your small group members. Small group staff will make sure that everyone has a chance to contribute to the skit. Your group will be assigned an etiquette topic. Brainstorm ideas with your other small group members, including staff, and feel free to use personal examples. Consider using props, signs...be CREATIVE! Everyone has the right not to participate or to stop participating if you feel uncomfortable. Most of all...have FUN!

Refer to the list of "Disability Etiquette Tips" below to help you develop your skits

-Disability Etiquette Topics (assigned by group):

Group 1: People who are deaf or hard of hearing.

Group 2: People who are blind or low vision.

- Group 3: People who use wheelchairs or have other mobility disabilities.
- Group 4: People with hidden or learning disabilities.
- Group 5: People with developmental/intellectual disabilities or Autism.

Disability Etiquette Tips

Here are some common disability etiquette tips:

- When introduced to a person with a disability, it is appropriate to offer to shake hands. People who have limited hand use or who wear an artificial limb can usually shake hands. (Shaking hands with the left hand is an acceptable greeting.)
- Remember that people with disabilities, like all people, are experts on themselves. They know what they like, what they do not like, and what they can and cannot do.
- If you offer assistance, wait until the offer is accepted. Then listen to or ask for instructions. Do not insist or be offended if your offer is not accepted.
- Don't be afraid to ask questions when you're unsure of what to do.
- Usually people with disabilities do not want to make the origin or details of their disability the first topic of conversation.

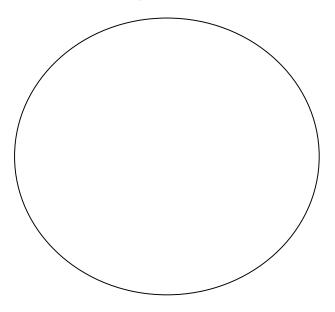
- Avoid asking personal questions about someone's disability. If you must ask, be sensitive and show respect.
- A personal assistant or a sign language interpreter may accompany people with disabilities. Always direct your communication to the individual with a disability and not to the companion.
- Use a normal speaking tone and style. If someone needs you to speak in a louder voice, he or she will ask you to do so.
- Don't be embarrassed to use common expressions such as "I've got to run now," "See you later," or "Have you heard about" even if the person doesn't run, see, or hear well. People with disabilities use these phrases all the time.
- Be aware that many people can have disabilities that are not apparent. Just because you cannot see a disability does not mean it doesn't exist.
- Be considerate of the extra time it might take a person with a disability to get some things done.
- Give unhurried attention to a person who has difficulty speaking. Don't pretend to understand when you don't; ask the person to repeat what he or she said.
- Speak calmly, slowly, and directly to a person who has a hearing impairment. Don't shout or speak in the person's ear. Your facial expressions, gestures, and body movements help in understanding. If you're not certain that you've been understood, write your message.
- Greet a person who is visually impaired by telling the person your name and where you are. When you offer walking assistance, let the person take your arm and then tell him or her when you are approaching inclines or turning right or left.
- Avoid excessive praise when people with disabilities accomplish normal tasks. Living with a disability is an adjustment, one most people have to make at some point in their lives, and does not require exaggerated compliments.
- Avoid terms that imply that people with disabilities are overly courageous, brave, special, or superhuman.
- Respect all assistive devices (e.g., canes, wheelchairs, crutches, communication boards, service dogs, etc.) as personal property. Unless given specific and explicit permission, do not move, play with, or use them.
- Don't pet a guide or companion dog while it's working.

- Make community events available to everyone. Hold them in wheelchair accessible locations.
- When planning a meeting or other event, try to anticipate specific accommodations a person with a disability might need.
- Relax. Anyone can make mistakes. Offer an apology if you forget some courtesy. Keep a sense of humor and a willingness to communicate.

If you don't know.....ASK!

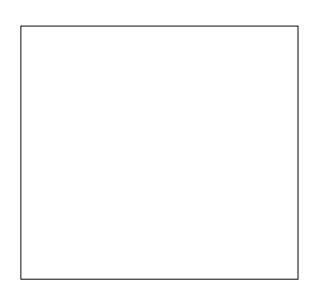
DEBRIEF ACTIVITY Circle, Square, Triangle, and Hexagon

CIRCLE: A question going around in my mind...

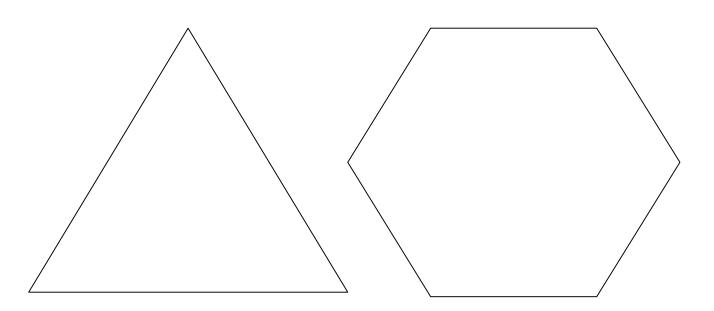


TRIANGLE: Three important points to remember...

SQUARE: Something that squares with my beliefs...



HEXAGON: An idea I'm having a hard time being comfortable with...



DAILY PROGRAM SCHEDULE TUESDAY, JULY 23, 2013

DAILY THEME: Disability History, Culture and Community

7:00 a.m. – 8:30 a.m.	BREAKFAST Desmond Hall	
8:45 a.m. – 9:15 a.m.	SMALL GROUPS Desmond Hall Small Meeting Rooms	
	 Discussion on Leadership 	
	 Overview of the day 	
	 Continue practicing disability etiquette skits 	
9:30 a.m. – 11:00 a.m.	LARGE GROUP – YLF X GAMES	
	 Small Groups announce their group names 	
	 Participate as a team in different "YLF X Games Events" 	
11:15 a.m. – 12:00p.m.	LARGE GROUP – DISABILITY HISTORY and CULTURE Desmond Hall	
	 Group 1 introduces presenter 	
	 Presentation on "Disability History" – Vivian Wong 	
12:00 p.m. – 1:00 p.m.	LUNCH Residence Dining Hall	
1:15 p.m. – 2:15 p.m.	LARGE GROUP - DISABILITY ETIQUETTE SKITS Desmond Hall Large Room	
	 Individual small groups to perform etiquette skits showing the do's and don't's 	

2:15 p.m. – 3:00 p.m.	of interacting with people with different types of disabilities. LARGE GROUP –ARTS PERFORMANCE Desmond Hall Large Room	
	 Group 2 introduces performer Interactive Arts Performance – Mark Goffney 	
3:15 p.m. – 4:45 p.m.	SMALL GROUPS Desmond Hall Small Meeting Rooms	
	 Continue discussion on leadership, talk about YLF X Games, disability history presentation, and "Disability Etiquette Skits" 	
	 "Talking About Disability" Activity 	
	 Social and Medical models of disability 	
	 "Fill in the Blanks" Activity 	
	 "Leadership Compass" Activity 	
5:00 p.m. – 6:00 p.m.	DINNER Barbecue by Pool Lawn Area o "Dream Achievers" Performance	
6:15 p.m. – 8:30 p.m.	ALUMNI SHARING Desmond Hall large and small rooms	
	 YLF Alumni and other young staff leaders with disabilities will lead discussions about college, employment, living independently, bullying, advocacy, dating & relationships and more. 	
	DELEGATES PREPARE FOR TALENT	
8:30 p.m. – 10:00 p.m.	SHOW (STAFF MEETING FOR ALL OTHERS)	
8:30 p.m. – 10:00 p.m.	SHOW (STAFF MEETING FOR ALL OTHERS) Desmond Hall	
8:30 p.m. – 10:00 p.m. 9:00 p.m. – 10:00 p.m.	(STAFF MEETING FOR ALL OTHERS)	
	(STAFF MEETING FOR ALL OTHERS) Desmond Hall	

QUALITIES OF A LEADER

(Tuesday)

Dictionary definition of a leader: (1) the person who leads or commands a group, organization, or country (2) a person followed by others

Your definition of a leader:

Who are some leaders in your life?

What qualities make a great leader? (For example: courage, trust, teamwork)

REMEMBER-THE FIRST PERSON THAT YOU LEAD IS YOU! You must first show yourself that you can do it and then share that with others.

"TALKING ABOUT DISABILITY" ACTIVITY (Tuesday)



Directions:

In your small groups, everyone writes on post-its one positive thing about their disability and one negative thing. Put all the positive things into a stack (or bowl) and put the negative things into a different stack (or bowl). Then each person will pull one post-it from each stack (making sure that they don't pull their own). Go around the group and each person reads aloud the post-its they pulled. Participants can choose to share which post-it they wrote, if they like.

Discussion Questions:

- 1. How did you feel to hear your peers' perspective on their disabilities?
- 2. Have you ever felt the way that they do? Have you ever felt differently?
- 3. What does this say about the common experience of disability?
- 4. How would you have handled your disclosure conversation at work, as opposed to in a group of your peers?
- 5. How would you have handled the disclosure of your disability in a school setting?

Adapted from the Maine Mentoring Partnership, <u>411 on Disability</u> <u>Disclosure Activities</u>, 2006

SOCIAL AND MEDICAL MODELS (Tuesday)

MEDICAL MODEL

- Disability is seen as something that a person should not want.
- Disability is bad.
- Disability is a personal problem.
- Curing people or making them seem less disabled will make their problems better.
- Only professionals can help the disabled person fit in and be accepted in society.

SOCIAL MODEL

- Disability is only a difference, just like gender or race.
- Being disabled is neither good nor bad; it's just part of who you are.
- Problems occur when a person with a disability tries to function in an inaccessible society.
- A change in society (like making things accessible for everyone) will lessen many of the problems and issues that people with disabilities experience.
- Change can come from a person with a disability, an advocate, or anyone who wants people with disabilities to be included equally in society.

FILL IN THE BLANKS (Tuesday)

Directions: Go around the room and find someone who can sign their name to fill out each of these sentences. Each person can sign no more than two sentences on your worksheet!

- 1. _____ has advocated for his/herself.
- 2. _____ has advocated for someone else.
- 3. _____ has been teased because of his/her disability.
- 4. _____ has been physically bullied because of his/her disability.
- 5. _____ has been left out of social situations (parties, etc.) because of his/her disability.
- 6. _____ has at least five friends with disabilities.
- 7. _____ has a hard time learning at school.
- 8. _____ has had painful medical treatments.
- 9. _____ has had a hard time asking for or getting accommodations.
- 10. _____ understands what accommodations are needed for his/her disability.
- 11. _____ has been discriminated against because of his/her disability.
- 12. _____ has been called names because of his/her disability.

LEADERSHIP COMPASS (Tuesday)

Objective

The Leadership Compass provides a tool for understanding how they approach life and how it can differ from how others approach life. One key to effective leadership is to be flexible within your own leadership style and open to others whose styles differ from your own.

North: The "Get It Done" Person

Leadership Style

- Assertive, active, and decisive.
- Likes to be in control and determine the course of events.
- Quick to act, expresses urgency for others to act quickly also.
- Enjoys challenging people and situations.
- Thinks in terms of the "bottom line."
- Likes a quick pace and the fast track.
- Courageous, ambitious, and confident.
- Perseveres Not stopped by "NO."
- Goal-centered, and ambitious.
- Hardworking leader who is comfortable being in front.
- Value words "Do it now!" "I'll do it."

Best Ways to Work with a North

- Present your case quickly, clearly, and with enthusiasm and confidence
- Let them know they will be involved their payoff and their role
- Focus on the "challenge" of the task.
- Provide them with plenty of autonomy.
- Establish timelines and stick with them.
- Give them positive, and public recognition.
- Use them to complete tasks that require motivation, persuasion, and initiative.

South: The Nurturer

Leadership Style

- Friendly, and likeable team player.
- Allows others to feel important.
- Supportive, nurturing and caring towards colleagues.
- Willing to trust others' statements at face value.
- Peace-loving, sympathetic, and helpful.
- Feelings-based, trusts own emotions, and intuition as truth.
- Able to focus on the present moment.
- Process-centered.
- Generous, non-competitive and likes to build on the ideas of others.
- Value words: "Right" and "Fair."

Best Ways to Work with a South

- Remember process, attention to what is happening with the relationship between you.
- Justify your decisions around values and ethics.
- Appeal your relationship with this person and his or her other relationships.
- Listen hard and allow the expression of feelings and intuition in logical arguments.
- Be aware that this person may have a hard time saying "NO" and may be easily influenced.
- Provide plenty of positive reassurance and likeability.
- Let the person know you like them and appreciate them.

East: The Visionary

Leadership Style

- Innovative, creative and sees the big picture.
- Very idea oriented, focuses on future thought.
- Risk-taker, adventurous, and spontaneous.
- Has insight into mission and purpose.
- Looks for overarching themes and ideas.
- Appreciates a lot of information.
- Strong spiritual awareness, free spirited, and unconventional.
- Likes to experiment and explore.
- Value words: "Option" and "Possibility."

Best Ways to Work with an East

- Show appreciation and enthusiasm for ideas.
- Listen and be patient during idea generation.
- Avoid criticizing or judging ideas.
- Allow and support divergent thinking.
- Provide a variety of tasks.
- Provide help and supervision to support detail and project follow through.

West: The Analyst

Leadership Style

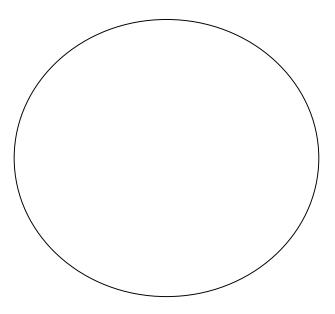
- Seen as practical, dependable, and thorough.
- Provide planning and resources to others.
- Moves carefully, deliberately, and follows procedures and guidelines.
- Uses data to make logical and analytical decisions.
- Weighs all sides of an issue, balanced.
- Introspective, self-analytical, focused, and reserved.
- Careful, thoroughly examines people's needs in situations.
- Works well with existing resources gets the most out of what has been done in the past.
- Skilled at finding the fatal flaw in an idea or a project.
- Value words: "Objective," and "Organized."

Best Ways to Work with a West

- Allow plenty of time for decision-making.
- Provide data objective facts and figures that a West can trust.
- Don't be put off by critical "NO" statements.
- Minimize the expression of emotion and use logic when possible.
- Appeal to tradition, a sense of history, and correct procedures.

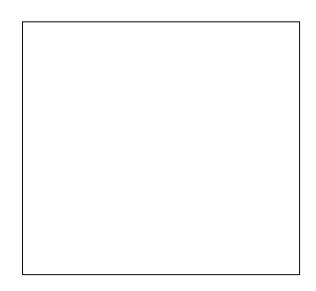
DEBRIEF ACTIVITY

CIRCLE: A question going around in my mind...

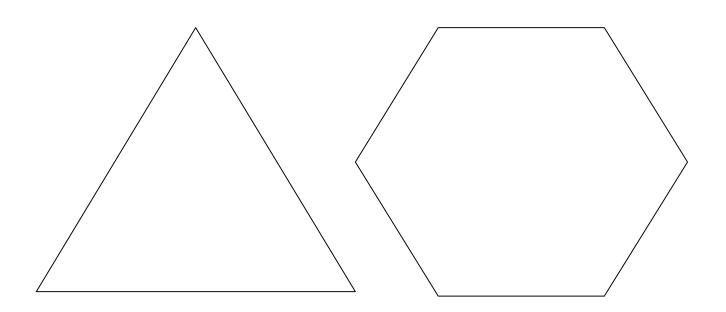


TRIANGLE: Three important points to remember...

SQUARE: Something that squares with my beliefs...



HEXAGON: An idea I'm having a hard time being comfortable with...



Circle, Square, Triangle, and Hexagon

DAILY PROGRAM SCHEDULE

WEDNESDAY, JULY 24, 2013

DAILY THEME: Discovering Resources to Reach Our Goals

7:00 a.m. – 8:30 a.m.	BREAKFAST Residence Dining Hall	
8:45 a.m. – 9:15 a.m.	SMALL GROUPS Desmond Hall Small Meeting Rooms	
	 Discuss Alumni Sharing. Prepare for the Resource Fair and Career Panel. 	
9:30 a.m. – 10:45 a.m.	LARGE GROUP ASSISTIVE TECHNOLOGY AND RESOURCE FAIR Desmond Hall – inside and outside	
	 Exhibitors will demonstrate assistive technology and other resources, including adaptive computer technology, accessible vehicles, and college resources. 	
11:00 a.m. – 12:00 p.m.	CSUS CAMPUS TOUR - BOOKSTORE Visit in small groups	
12:00 p.m. – 1:15 p.m.	LUNCH ON CAMPUS CSUS Student Union Food Court	
1:30 p.m. – 2:00 p.m.	LARGE GROUP Voting and Legislative Advocacy Presentation	
	 Dolores Tejada talks about the importance of voting and how you can advocate for your rights. 	
2:00 p.m. – 3:30 p.m.	LARGE GROUP Panel: Living On My Own & Reaching My Career Goals Desmond Hall Large Room	

3:45 p.m. – 4:45 p.m.	 Group 3 introduces panel presenters. SMALL GROUPS Desmond Hall Small Meeting Rooms 	
	 Discuss technology fair and career panel from earlier in the day. Come up with policy issues and recommendations to discuss with legislators tomorrow at the Capitol. Prepare for the Capitol visit and YLF Luncheon. Work on Personal Leadership and Advocacy Plan. 	
5:00 p.m. – 6:00 p.m.	DINNER Residence Dining Hall	
6:15 p.m. – 7:15 p.m.	 SMALL GROUPS Desmond Hall Small Meeting Rooms "Create it, Believe it, Achieve it!" Activity. Work on Personal Leadership and Advocacy Plan. 	
6:15 p.m. – 7:15 p.m. 7:30 p.m. – 9:00 p.m.	 Desmond Hall Small Meeting Rooms "Create it, Believe it, Achieve it!" Activity. Work on Personal Leadership and Advocacy 	
	 Desmond Hall Small Meeting Rooms "Create it, Believe it, Achieve it!" Activity. Work on Personal Leadership and Advocacy Plan. LARGE GROUP: TALENT SHOW 	

"CREATE IT, BELIEVE IT, ACHIEVE IT" (Wednesday)

<u>DIRECTIONS</u>: You are provided with eight (8) picture frames. Each picture frame represents a category that is a part of independent living. For each category, you can either: A) draw a picture that represents this area of your life after high school or B) use the space to write words that will help you write a poem or song about your life after high school. Read the questions in each category to help you plan and create your picture, poem, or song.

Career/Employment

- 1. What career field am I interested in after high school?
- 2. Will I work full-time or part-time?
- 3. What will my workplace look like?
- 4. If I am undecided about my future career/employment, what will I do instead?



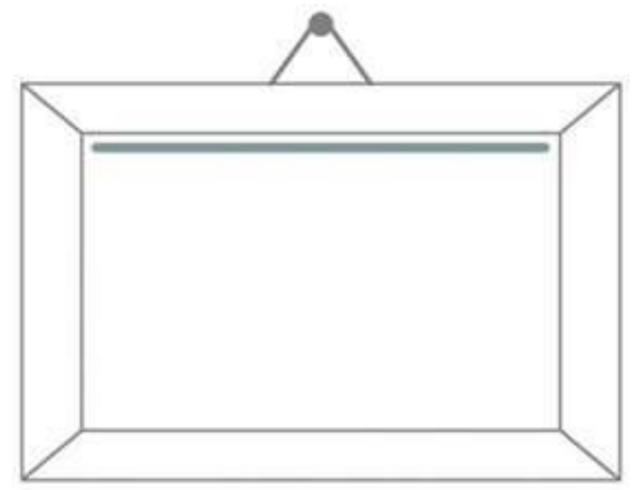
Training/Education

1. What kind of college do I plan on attending after high school? A community college or a four (4) year college?

2. What kind of training would help me after high school? Is it vocational or a different kind?

3. What will I do in college or in my training program?

4. If I am undecided about my training/education after high school, what will I do instead?



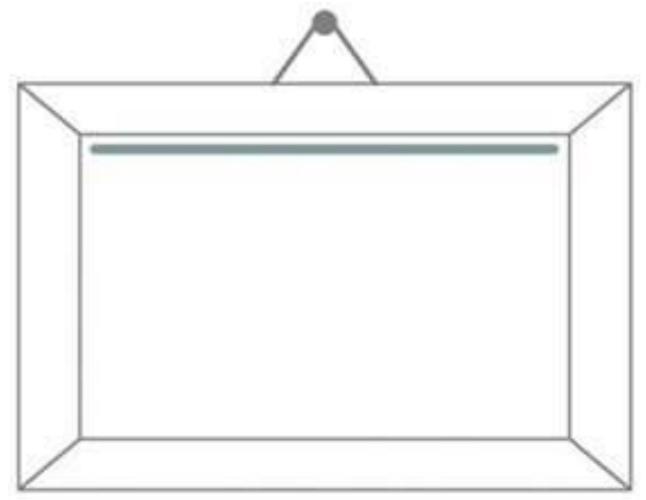
Transportation

1. What kind of vehicle will I drive? Car or a van?

2. What kinds of modifications will be in my vehicle?

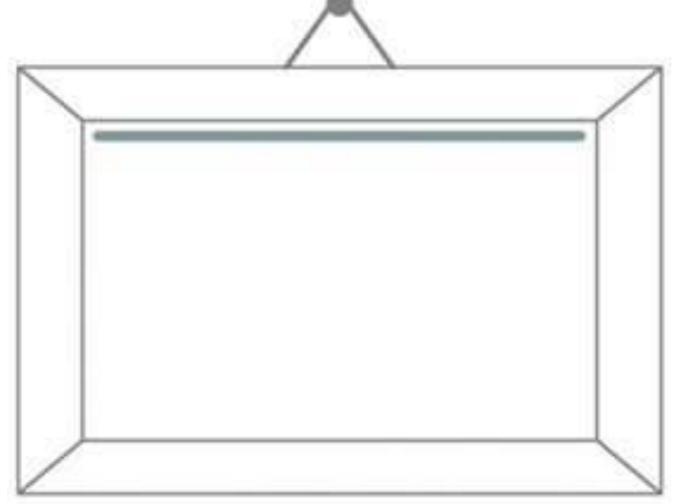
3. What other kinds of transportation options are there? Paratransit? Bike? Public bus?

4. If I don't have access to a vehicle or public transportation, how will I get around?



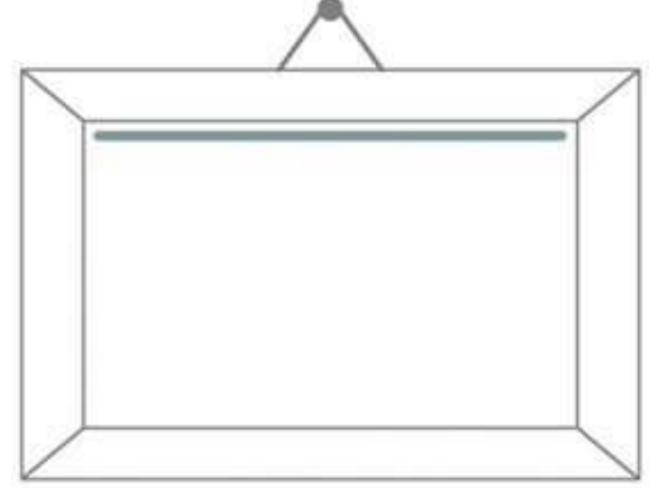
<u>Housing</u>

- 1. If I live with my parent (s)/guardian, what will my room look like?
- 2. If I rent a room in a house, what kind of house will it be?
- 3. If I live in an apartment, what will it look like?
- 4. If I don't have plans to live with my parent (s)/guardian, where will I live?



Recreation/Leisure

- 1. What kinds of social and recreation activities will I participate in?
- 2. What are my hobbies?
- 3. What kinds of things will I do with my friends?
- 4. What other options can I do for fun?

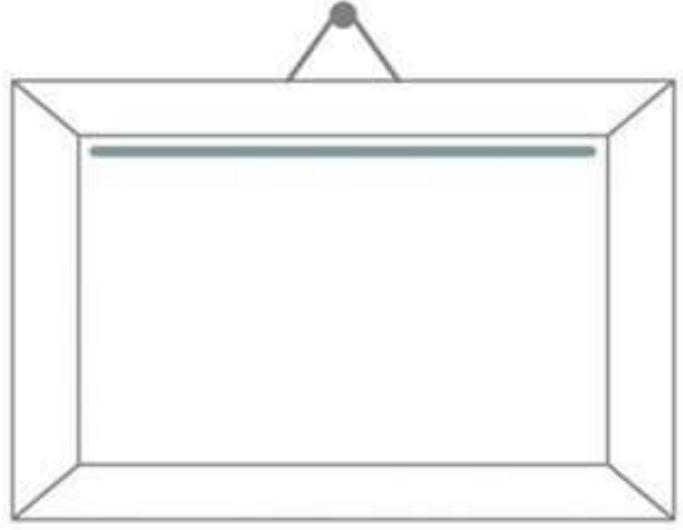


Community Resources

1. What kinds of services/agencies will be available in my community? (e.g. community college. Dept. of Rehabilitation, Independent Living Center).

2. What kinds of places do I want to live close to? (e.g. library, grocery store, bank).

3. If I don't know what community resources will be available, where can I find more information?



Life Skills

1. What tasks will I do where I live? (e.g. laundry, cooking, housekeeping chores).

2. How will I schedule appointments and stay organized?

3. Which people will assist me on a daily basis? (e.g. personal care assistant, interpreter, family member).

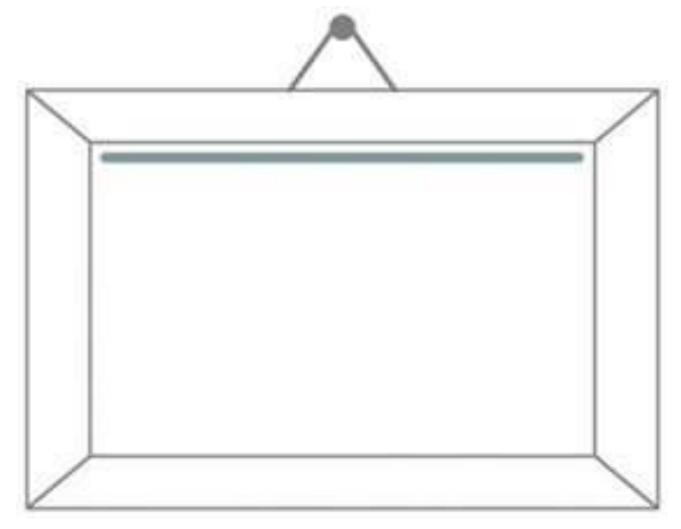
4. What kinds of assistive technology will I use?



Financial/Economic

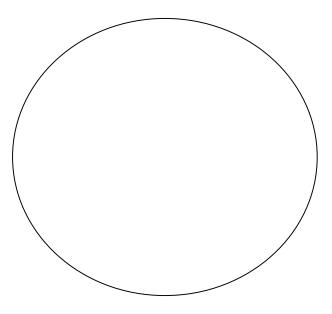
1. What kinds of accounts will I have? Checking account, savings account or both?

- 2. What will I use to access my finances? (e.g. ATM card, checks, cash).
- 3. What kinds of things will I have to pay for? (e.g. rent, car insurance, utilities).
- 4. How will I budget to plan my finances/expenses?



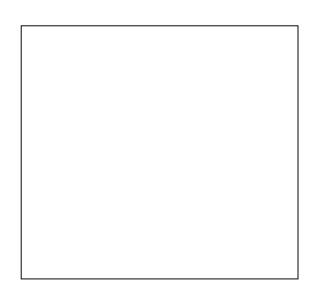
DEBRIEF ACTIVITY Circle, Square, Triangle, and Hexagon

CIRCLE: A question going around in my mind...

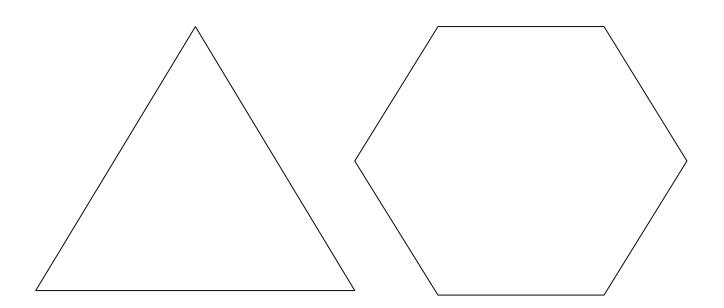


TRIANGLE: Three important points to remember...

SQUARE: Something that squares with my beliefs...



HEXAGON: An idea I'm having a hard time being comfortable with...



DAILY PROGRAM SCHEDULE

THURSDAY, JULY 25, 2013

DAILY THEME: Getting Involved in the Community

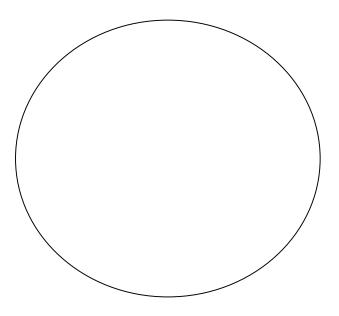
6:45 a.m. – 7:45 a.m.	BREAKFAST Desmond Hall	
8:00 a.m.	BUSES LEAVE FOR STATE CAPITOL Outside Desmond Hall	
	 All delegates and staff meet in small groups in front of Desmond Residence Hall at 7:45 a.m. Buses begin boarding promptly at 8 a.m. and leave exactly at 8:15 a.m.!!!! 	
	\circ Stay with Small Groups upon arriving at Capitol.	
8:45 a.m. – 9:15 a.m.	PREPARE FOR LEGISLATIVE VISITS Outside State Capitol (West Steps)	
	 Small Groups meet with legislative visit leaders to finish preparing for legislative visits. 	
9:15 a.m. – 9:45 a.m.	WELCOMING REMARKS, GROUP PHOTO, PRESS SESSION Outside State Capitol (West Steps)	
	\circ Group photo and press session.	
	$_{\odot}$ Welcoming remarks by YLF Planning Partners:	
	 Tony Sauer, Director, Department of Rehabilitation 	
	 Dennis Petrie, Deputy Director, Employment Development Department 	
	 Catherine Kelly Baird, Friends of Californians with Disabilities, Inc. 	
	 Antoine Hunter, Dancer, Deaf community leader 	

10:00 a.m. – 10:45 a.m.	MEETING IN GOVERNOR'S OFFICE How to Be an Effective Change Agent State Capitol, Governor's Office	
	 Group 4 introduces speakers. 	
	 Governor's Cabinet staff. 	
	 Sarah Triano, YLF Alumna, Executive Officer of the California Committee on Employment of People with Disabilities. 	
11:00 a.m. – 11:45 p.m.	VISITS TO LEGISLATORS' OFFICES State Capitol in assigned small groups	
12:15 p.m. – 2:30 p.m.	YLF LUNCHEON Sacramento Convention Center (detailed program schedule distributed at luncheon site)	
	 Delegates dine with adults with disabilities, discuss career options and identify mentorship opportunities 	
	 Group 6 introduces presenters: 	
	Dani Duran, YLF AlumnaBobby McMullen, Keynote Speaker	
3:00 p.m. – 4:00 p.m.	STATE CAPITOL TOURS State Capitol in assigned small groups	
4:00 p.m.	RETURN TO CSUS CAMPUS	
	 Buses load at 4 p.m. and leave promptly at 4:15 p.m. for return trip to CSUS! 	
	 Meet with your small group at morning drop-off site on 10th Street. 	
5:00 p.m. – 6:00 p.m.	DINNER Residence Dining Hall	
6:15 p.m. – 7:15 p.m.	SMALL GROUPS Desmond Hall Small Meeting Rooms	
	\circ Discuss the day at the Capitol and the Luncheon.	
	 Finish selecting (and recording) a major policy issue or recommendation. 	

	 Work on Personal Leadership and Advocacy Plans. 	
	 Review check-out process. 	
	 Daily reflection/ 	
7:30 p.m. – 10:00 p.m.	DANCE	
10:00 p.m.	PERSONAL TIME FOR DELEGATES	
	 Begin packing for trip home. 	
10:30 p.m.	LIGHTS OUT	

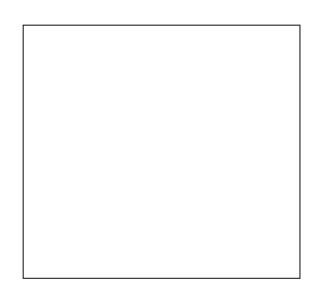
DEBRIEF ACTIVITY Circle, Square, Triangle, Hexagon

CIRCLE: A question going around in my mind...

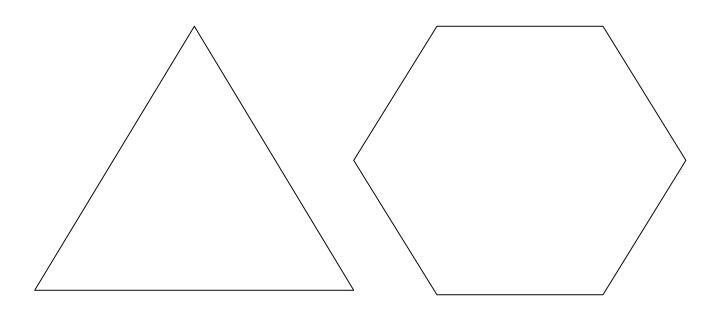


TRIANGLE: Three important points to remember...

SQUARE: Something that squares with my beliefs...



HEXAGON: An idea I'm having a hard time being comfortable with...



DAILY PROGRAM SCHEDULE

FRIDAY, JULY 26, 2013

DAILY THEME: Now We Begin the Rest of Our Lives

7:30 a.m. – 8:30 a.m.	BREAKFAST Residence Dining Hall		
8:45 a.m. – 10:30 a.m.	SMALL GROUPS FINAL ACTIVITIES AND CHECK- OUT Desmond Hall small meeting rooms		
	 Group finalizes statement on one major social or policy recommendation. 		
	 Identify delegates interested in serving on statewide advisory groups regarding disability issues. 		
	 Discuss delegates' responsibilities as alumni of YLF. 		
	 Complete Personal Leadership and Advocacy Plan. 		
	\circ Write letter to self and letter to sponsor.		
	$_{\odot}~$ "What People Like and Admire About Me" Activity.		
	 Prepare to check out of dorms. 		
	FINAL CHECK-OUT ACTIVITIES		
	 Delegates complete all final check-out activities with assistance from their Small Group staff, including: 		
	 Turn in room key and meal card (and receive \$5 stipend). 		
	 Take care of sheets and towels. 		
	 Make sure room is empty and clean. 		
10:45 a.m. – 12:15 p.m.	LARGE GROUP CLOSING SESSION Desmond Hall Large Room		
12:30 p.m.	BOX LUNCH PROVIDED (To eat on site or take to travel site)		
1:30 p.m.	BUSES LOAD		
2:00 p.m.	BUSES LEAVE		
	- /		

LETTER TO MYSELF

Date: July 26, 2013

Dear _____:

Today is the last day of our Youth Leadership Forum. When I return to my community, I want to remind myself to do the following things to make my life and my community better.

Sincerely,

LETTER TO DONORS OF YOUTH LEADERSHIP FORUM

July 26, 2013

Dear Friend:

I am writing to thank you for your generous support of the California Youth Leadership Forum for Students with Disabilities.

I was very honored to be chosen to represent my community at this forum. What I especially liked and learned at the forum was:

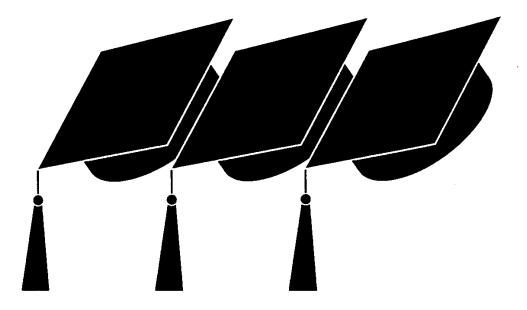
Thank you again,

From (City): _____

My	name:	
7.		
8.		
9.		
10.		
11.		
12.		
13.		

What People Like and Admire About Me

CONGRATULATIONS! Remember to keep in touch!



What's next after YLF?

- Become a member of YLF Alumni! Check out our Facebook page, "CA Youth Leadership Forum Alumni"
- Tell your friends, family, and other youth with disabilities all about Youth Leadership Forum!
- Check out the Youth Transition Toolkit (<u>www.tknlyouth.org</u>) and use some of the resources included!
- Get in touch with people you met at the Luncheon, speakers from the week, staff and delegates!
- Use what you learned at YLF to continue to be a leader in your community!!

PERSONAL LEADERSHIP AND ADVOCACY PLAN

PERSONAL LEADERSHIP AND ADVOCACY PLAN CREATED DURING THE CALIFORNIA YOUTH LEADERSHIP FORUM (YLF) FOR STUDENTS WITH DISABILITIES

Delegate's Name

The information below will assist me in developing my leadership potential and creating an action plan based on a goal I would like to achieve. To complete this plan, I will imagine my life one (1) year from now and create specific steps on how to achieve a goal.

DIRECTIONS: Complete each of the sections below.

1. "My GOAL"

(GOALS RELATED TO OVERCOMING: A) A PERSONAL OBSTACLE, B) TO EDUCATION, TO WORK, C) TO SOLVING A WORLD PROBLEM OR D) A COMMUNITY SOCIAL ISSUE)

The goal I want to achieve in the next year is:

Some reasons why I want to achieve this goal:

CONTINUED ON NEXT PAGE

PERSONAL LEADERSHIP AND ADVOCACY PLAN continued

2. "PERSONAL RESOURCES"

(DEVELOPING PERSONAL SKILLS TO BE ABLE TO ACHIEVE GOAL)

Some of my assets (strengths, talents, or hobbies) I have to achieve my goal:

Some people or resources I have to help me achieve my goal:

3. "PROS AND CONS"

(IDENTIFYING POSITIVE AND NEGATIVE OUTCOMES IN ACHIEVING GOAL)

Some positive things that will come from achieving my goal:

A personal challenge that I will face as an opportunity for my growth and development in achieving my goal:

PERSONAL LEADERSHIP AND ADVOCACY PLAN continued

4. "STEP-BY-STEP"

(CREATING A CHECKLIST TO ACHIEVE YOUR GOAL)

The first thing I will do to achieve my goal is:

The additional things I will do to achieve my goal are:

5. "PLAN MY ACTIONS" (DEVELOPING ACTIONS TO ACHIEVE MY GOAL)

Specific tasks I plan to do:

Specific opportunities I plan to seek out:

PERSONAL LEADERSHIP AND ADVOCACY PLAN continued

6. Specific people I will ask to help me:

Specific equipment or technology I will explore using:

*Reminder - Complete my employment resume!

TOOL BOX WITH MORE SESSION ACTIVITIES AND HELPFUL INFORMATION

On the following pages are:

- Youth Transition Toolkit Resource Flyer
- ***** A list of Leaders from the Disability Community
- * A list of Quotations about Leadership
- An Article about "Disability Culture"
- How to Join California YLF Alumni
- List of YLF 2013 Sponsors



YOUTH I RANSITION I OOLKIT:

A GUIDE FOR YOUTH WITH DISABILITIES TRANSITIONING TO ADULTHOOD IN CALIFORNIA

Things are About to Change is a comprehensive transition "toolkit" and resource guide for youth with disabilities ages 12 to 21+. The overall objective of the toolkit is to help transitioning youth become better prepared and more successful transitioning from youth to adulthood.

Designed to provide information on transition for youth with disabilities, the toolkit contains worksheets, tips for parents and valuable resources on a number of transition-related topics!

I OPICS INCLUDE:

- ABOUT TRANSITION
- HEALTHCARE
- EMPLOYMENT
- FINANCES
- EDUCATION
- INDEPENDENT LIVING
- SOCIAL/RECREATION

The toolkit is available at:

www.tknlyouth.info

For more information, contact Kim Hogan Phone: (916) 653-2536 E-mail: kim.hogan@edd.ca.gov



Transition Toolkit –'A Guide for Youth with Disabilities Transitioning to Adulthood in California'

The overall objective of the toolkit is to help transitioning youth become better prepared and more successful in transitioning from youth to adulthood. The toolkit contains worksheets, tips for parents and valuable information and resources on a number of transition-related topics. Chapters included in the toolkit are Independent Living, Employment, Healthcare, Education, Finances and Social and Recreational Opportunities. The toolkit is available on the <u>www.tknlyouth.info</u> website, and PDFs of entire chapters and individual worksheets are available to download under the "Resources" section. The following presents an overview of each chapter of the toolkit.

Education

This chapter is designed to empower you while you're in high school and help you transition into college or other education after high school. Information is provided to assist you, your family and your school as you work together to plan ahead for the most effective transition plan.

The Education Chapter includes information, tips, and resources on the following topics:

- Person-Centered Planning.
- Individualized Education Program (IEP) or 504 plan, Individualized Transition Plan (ITP) and Summary of Performance.
- Difference between a certificate of completion and a diploma.
- Understanding the differences between high school and college.
- Requesting accommodations in college.
- Financial aid and scholarships.
- Alternatives to college, including vocational training and regional occupation programs.

Independent Living

This chapter helps you start thinking about making the transition into living on your own. Resources are provided which allow for the chance to live a fulfilling and successful life.

The Independent Living Chapter includes information, tips and resources on the following topics:

- Background on disability history, including the disability rights and independent living movements and information on Ed Roberts.
- Worksheet on disability self-awareness.
- Finding accessible housing, buying a home, finding roommates and housing rights.
- Finding and paying for a personal care attendant.
- Mentorship.

Employment

Designed to help you transition into employment, this chapter includes information on a wide range of activities, which can help you enter the world of work.

The Employment Chapter includes information, tips and resources on the following topics:

- Choosing a career that fits with your interests and abilities.
- Resume writing and successful interviewing techniques.
- Building work experience, including volunteerism and internship programs.
- How to find a job.
- Resources to learn about work incentives and learn about the impact of employment on cash and healthcare benefits.
- Rights related to job accommodations.
- Disability disclosure, and how to decide when (and whether) to disclose your disability.
- Personal assistance services at work.

Finances

Money management can be intimidating; this chapter will give you the tools and resources needed to learn how to take control of your financial future.

The financial chapter includes information, tips, and resources on the following topics:

- Basic budgeting: how to balance a checkbook, pay bills, etc.
- Credit cards and how to avoid getting into debt.
- Real-life stories about credit cards and car loans.
- Tips for parents on teaching their child to start managing their own finances.

Healthcare

This chapter provides information and resources, which encourage you to begin to take charge of your own healthcare needs.

The healthcare chapter includes information, tips and resources on the following topics:

- Worksheets on handling your own health-related needs.
- Keeping track of vital healthcare information, including medications, making doctors appointments and communicating with your doctor.
- Different ways to access health insurance.

Social and Recreational Opportunities

This chapter provides you with resources on how to escape the daily grind of work and/or school and take full advantage of the social programs available.

The social recreation chapter includes information, tips, and resources on the following topics:

- Clubs and adaptive sports programs, which are designed specifically for youth with disabilities.
- Ways to become involved in the disability community and advocate for the rights of people with disabilities.
- Best ways to travel with a physical disability.

"IN SEARCH OF DISABILITY CULTURE"

An article by Miriam Braunstein

Although disabled since age eight, I was almost 19 years old before I had any inkling that there was something people call disability culture.

I first heard about it three years ago from a friend living in Berkeley, California, who happened to be picking up a few hours working for Hale Zukas, a founder of the Berkeley Center for Independent Living. Zukas had also helped build the World Institute on disability alongside its founders, Judith Heumann, Joan Leon and the late Ed Roberts. Then, of course, those names meant nothing to me.

"There's a magazine with angry letters," my friend said, referring, I believe, to *The Disability Rag.* "And there's one with the quadriplegic *Playboy* model. They have stories, ads, stuff like that."

Well, who would believe a story like that? As proof, he sent copies of these things, along with ADAPT sticker cutouts and WID literature. I was mesmerized. Nineteen years as a Jew, with all the history it entails, had not prepared me for anything like this. At first, even the idea of catheter ads was liberating. I had no idea that disability was discussed outside the hospital wards. I didn't know that disabled people talked to one another, much less organized.

As intrigued as I was, my able-bodied parents were wary. As my interest grew, they moved from nervous to terrified and finally to combative.

"What," my mother asked, "is with this crippled thing? Why are you reading this stuff?"

"Well, I like to read about other disabled people," I said, or something near. "I like to hear what they think." They think like me, is what I was thinking, but not saying.

"Well, you have nothing in common with them," said my father, and that was all they wanted to hear of it. Culture was important things, they said, like your religion. A disease shouldn't define you. To their minds, as to the minds of any number of non-disabled people operating under old notions about the nature of disability, I was a nice Jewish girl who was sick. And even if it wasn't my fault, I certainly wasn't supposed to run around flaunting it, for heaven's sake. A little decorum and embarrassment, please! In other words, my disability was a circumstance, not a part of who I was.

A Skewed History

I was getting my first taste of sharing a common culture with those I increasingly felt were my people, and it was intoxicating. If this was disability culture, I had to find my own place in it, regardless of what any number of able-bodied people thought.

That is not as simple as it seems. It is easy to find signs of disability culture; I had the magazines, a bit of history and a feeling of kinship with the disabled community. I had *When Billy Broke His Head … and Other Tales of Wonder,* a couple of bios of famous gimps, a threatening bumper sticker and a real desire to find out who I was.

What I didn't have was a solid feeling of what, exactly, disability culture is or why it should be so upsetting to the able-bodied people in my world. And that is what I began looking for.

Steven Brown, a co-founder of the Institute on Disability Culture in Las Cruces, N.M., has spent a good deal of time considering the elusive combination of disability and culture. To Brown, it is the communal experience of oppression and resilience that generates the art, music, and literature of disability culture.

"Most importantly," Brown says, "we are proud of ourselves as people with disabilities. We claim our disabilities with pride as part of our identity."

It is, however, an identity that can be amazingly hard to come by. Unlike other established cultures, we have precious little family tradition; with the exception of some hereditary disabilities, disabled children are not usually born to disabled parents. Give Brown's model, which places the history of oppression that disabled people share firmly at its epicenter-this lack of intergenerational contact is a decided disadvantage.

"What we don't have are parents with disabilities teaching kids with disabilities," he says. "What we do have are people of an older generation teaching people of a younger generation."

The triumphs of modern medicine have gone a long way toward providing second and third generations. In the days when spinal cord injury was, at best, something you could survive but not live with, when muscular dystrophy and spina bifida were fatal and most other people with disabilities were kept in back bedrooms or in institutions, older disabled role models were hard to come by. Only after people with disabilities were let out of the house with Section 504, IDEA and, later, the ADA, and only after medicine advanced enough to keep us alive if not kicking, was there any chance of an oral history being discovered. It exists, says Brown, but it isn't easily accessible.

"We didn't think we had a history, "he says. "Well, we have one, but nobody thought it was worth telling."

If the key to disability culture lies in our history, as Brown suggests, then a whole new problem arises; namely, how to access that history. A sprinkling of books written in the past few years-*No Pity and Enforcing Normalcy,* for example - focus on disability history and several more at least touch on it, but before the early 1980s, very little was written on disability that wasn't clinical. Even less, with a few notable exceptions, was written by people with disability.

That is the biggest problem, says writer and performance artist Cheryl Marie Wade, who lives in Berkeley. If disability history is recorded by non-disabled people, it isn't really a part of disability culture.

"Disability culture," says Wade "is disabled people talking about ourselves." And it is able-bodied people, she says, who apportion money for the disabled artistic community – thus negating the point of disability culture.

"A lot of the programs were started by well-meaning able-bodied people," Wade says. "But the community outgrew the organizations, and the organizations don't reflect that. The paid positions are held by able-bodied people. They set the tone. They set the agenda."

As long as that is the case, she says, disability culture is a footnote to mainstream culture, "a subculture."

Wade says her work expresses, to the best of her ability, what it is to be disabled. She will scream, yell, and wave her bent hands in people's faces. That, she says, is one component of disability culture-to bring the existence of a whole group of people with an entirely separate agenda and lifestyle to the attention of the mainstream community. This is the part of disability integration that cannot be legislated.

"Just because we have ramps doesn't mean people look at us as human beings," Wade says. "The point is to say, 'Hey you, we're not just like you, but so what?"

"We didn't think we had a history. Well, we have one, but nobody thought it was worth telling."

-Steve Brown

Like Brown, Wade points to pride as a definitive part of culture. It was not until she threw the shawl that she used to hide her hands off her lap and out of her life that Wade was able to become an artist and confront society's view of the disabled.

A "Schizophrenic" Line

Paradoxically, disability culture is held to be both a means to insulate ourselves from the larger society and a means to integrate ourselves. Again, says Brown, it comes down to confidence and pride. If the disabled community can band together in its culture, it can force its way into the collective consciousness of mainstream culture.

"It's the opposite of anti-mainstream," Brown says. "It's not possible for people with disabilities to truly integrate until we are recognized as having pride in who we are as disabled people."

"We walk an almost 'schizophrenic' line," agrees John Kemp, CEO of Very Special Arts, an organization based in Washington, D.C., that funds disabled artists worldwide. "We talk inclusion, and then we talk disability pride."

Like Brown, Kemp says the two goals can coexist. Pride, he says, is making claims for our rights based on self-worth, and disability culture is expression of the ways in which we value ourselves and our contributions.

"A whole lot of people don't know how the arts can express what joyous lives we can have," Kemp says, and the ignorance includes disabled people.

There is no way of knowing how few or how many people actually understand disability pride, or really experience it. Most disabled college-age people were born after Section 504, and were still in their mid-teens when the ADA was passed. In spite of all the legislation, disability culture, history, pride and activism are still, for many people, an accidental find. They are spread primarily through community word-of-mouth, which doesn't work well in an isolated and fragmented population. Access to disability culture must be increased, Kemp says, if young people are to continue to help it to develop.

"We walk an almost "schizophrenic" line. We talk inclusion, and then we talk disability pride."

-John Kemp

"They need to know who their heroes are," he says. "It's a funny thing, because I was always told I had to compete in the 'real world.' Now I know that disability is a part of who I am, and young people need to know that, too." This realization, Kemp says, makes it possible for disabled people to compete to the best of their abilities without denying their disabilities.

Linda Carpenter, 27, who has a congenital disability, says that during her childhood, disabled role models were simply not available. Carpenter, though, says the lack of available "heroes" in the disabled world did not leave her isolated or without resources.

"It made me more mainstreamed, and I'm glad I was mainstreamed," she says. "I didn't really think it was a bad thing to be like everybody else." Carpenter learned that she could relate normally to able-bodied people. "I broke a lot of braces jumping off things like the other kids," she says.

In her 20s, and for reasons she doesn't yet understand, Carpenter initiated more relationships among her disabled peers. "I found some people I wanted to be friendly with, I suppose," she says. The need for guidance and camaraderie she responded to extends from people growing up with disabilities to people whose disabilities are acquired later in life.

Subcultures, Multicultural

When Detroit writer Clark Iverson developed epilepsy 16 years ago at age 20, he had no idea, he says, of the existence of disability culture.

"I grew up thinking one way, and I was forcibly made to think another way," Iverson says. "I've become aware [of disability culture] gradually, over the past 10 years or so. "Iverson's epilepsy is normally unnoticeable, so his involvement has come in spite of non-disabled friends who are puzzled by his attraction to disability issues. His primary commitment has been political, he says; most of disability culture is something that "falls under the heading of one of the things in life I haven't had time to pursue." He doubts that he'll become actively involved in other aspects of disability culture, a concept that to him is self-limiting anyway; he does not think such a large and diverse group can bond effectively. Congenital amputee Michael Paul of Warren, Mich., takes Iverson's doubt one step further; he says disability culture, while a trendy concept, has had little impact on his life. He doesn't believe any sort of true disability culture can exist at all. "The fact that there are non-disabled people in the world makes it impossible." Paul says. "We're not living on a gimp desert island. A leper colony is the closest we can come to disability culture-disability subculture, maybe."

Instead of pursuing disability culture, Paul says, disabled people should simply accept themselves and work on making mainstream culture accept our differences and appreciate our similarities. This concept is not necessarily at odds with disability culture, say Brown.

"Everybody is a part of different cultures," he says. "It's one more way to define yourself."

There is no consensus that I have found on what will happen to disability culture. Nobody can predict the development of a trend in its embryonic stages and, for now, that is precisely where disability culture is. It remains an inexact and distinctly flawed concept; hard to define, hard to find, hard to spread. Within it are any number of branches; it is, most say, about pride, and we can demonstrate our pride in many different ways.

But you don't have to define disability culture to notice it, to understand it or crave it. I suppose the worst fear of my Yiddeshe mama has been fulfilled; I have found another heritage to identify with. Just as surely as I want to visit Jerusalem, I want to make a pilgrimage to Berkeley – to see the first stirrings of the independent living movement. I apply myself to the history of ADAPT the way my grandfathers read the Talmud.

But as I bring disability culture into the stew of unlikely things that produced who I am, it becomes less urgent and all encompassing. Probably, it will eventually settle in next to all the other words I use to define myself: Jewish, Italian, female, brunette, whatever. It will become another part of my personality, integral but no overwhelming.

I went to my parents' house a while back to visit my mother, newly home from a jaunt to Israel. She was on a heritage kick, humming the Israeli anthem, brandishing a copy of the *Jerusalem Post* and handing out Hebrew name necklaces left and right.

"Here," she said, tossing one over my head. "So you don't forget who you are."

I put in on' it was pretty and would help and Hebrew-speakers who wonder who I am.

"You know, ma," I said, "I am still Jewish."

She waved that off, and leaned down to me. "Just remember," she murmured," where you come from."

Because it isn't until you know where you're from that you can figure out where you're going-as a disabled person or as anything else.

(Note: Published February 1997, "New Mobility" magazine. Reprinted with permission of the author exclusively for this YLF workbook. Please do not reprint.)

People with Disabilities Who are Recognized Leaders

During YLF, you will hear from and about many individuals with disabilities who have significantly changed our world for the better. We could never compile a list of "Who's Who" in the history of disability culture and advocacy without inadvertently omitting some remarkable people. But we decided to at least start a list for you to think about and add to. In our list below, we have placed an asterisk beside the names of those you may have an opportunity to meet with this week.

Mary Lou Breslin — Co-Founder of the Disability Rights Education and Defense Fund (DREDF) and Americans with Disabilities (ADA) advocate.

Marca Bristo — Instrumental in the passage of the ADA and President/CEO of Access Living of Metropolitan Chicago. First person with a disability to serve as part of the United States delegation to the United Nations, currently working to establish a UN convention on the rights of people with disabilities.

Catherine Campisi, Ph.D. — long time advocate for disabled students in higher education, Co-founder of the CA YLF, and retired director, State Department of Rehabilitation.

Tony Coelho — Former California Congressman and former chair, President's Committee on Employment of People with Disabilities, who helped disseminate YLF to more than thirty states and territories. Primary sponsor of the ADA.

Scott Cooper—Founder of the Disability Media Institute.

Hal Connolly — First U.S. Olympic gold medalist who performed with a major disability, and served as the executive director of the Special Olympics.

Susan Daniels —National disability advocate, former associate commissioner of the U.S. Department of Education's Rehabilitation Services Administration, and associate commissioner in the Administration on Developmental Disabilities at the Department of Health and Human Services.

Justin Dart, Jr.—Considered "godfather" of the disability rights movement and "father" of the ADA.

Senator Robert Dole — Former U.S. Senator, war veteran, and national disability advocate.

Richard Devylder—Former CIL director and disability emergency preparedness advocate. In 2010 was appointed as the US Department of Transportation's first senior advisor for accessible transportation.

Robert David Hall — Acclaimed actor ("CSI-Crime Scene Investigation," CBS Studios) and long-time disability advocate and volunteer member, Media Access Office (MAO).

Judy Heumann —Co-founder of the Independent Living Movement, former assistant secretary of the Office of Special Education and Rehabilitative Services World Institute on Disability, and primary leader in passage of the Americans with Disabilities Act (ADA).

Andrew Imparato — President and CEO, American Association for People with Disabilities (AAPD), Washington, D.C., and recognized national advocate.

I. King Jordan — National advocate and first deaf president of Gallaudet University, Washington, D.C.

Catherine Kelly Baird — Former executive director, California Governor's Committee on Employment of People with Disabilities and co-founder of the California Model Youth Leadership Forum (YLF) for Students with Disabilities.

Paul Longmore, Ph.D.—Late professor of history primarily responsible for promoting the theory of disability culture, San Francisco State University, co-founder in 1996 of San Francisco State's Institute for Disability Studies.

Bryon MacDonald — Father of California Workforce Inclusion Act, policy specialist for the World Institute on Disability (WID).

Marlee Matlin — Youngest actress, and only deaf performer to win the Academy Award for Best Actress in a Leading Role, Member of the National Association of the Deaf.

Christina Mills — Deputy Director of California Foundation for Independent Living Center (CFILC), former chair of the State Independent Living Council, California YLF Alumna.

*Rich Pimentel — internationally recognized trainer and co-author of the California Governor's Committee's "Windmills" training curriculum.

Brenda Premo — Former member, National Council On Disability (during drafting of the ADA) and former director, State Department of Rehabilitation.

Ed Roberts — Founder of the Independent Living Movement and co-founder of the Center for Independent Living (Berkeley, California) and the World Institute on Disability. First student with severe disabilities to attend the University of California, Berkeley. Appointed by Governor Jerry Brown as director of California Department of Rehabilitation (DOR) in 1976.

President Franklin Delano Roosevelt — First United States President who was a wheelchair user.

Tony Sauer–Disability Rights Advocate and current director of the State Department of Rehabilitation.

Gina Semenza—Former chair of the National Council on Disability's Youth Advisory Committee, staff to Senator Barbara Boxer, and California YLF alumna.

Sarah Triano—Alumni from the first CA YLF, and currently the executive officer of the California Committee on Employment of People with Disabilities. Co-founder of the Disability Pride Parade and the National Disabled Student Union.

NOTABLE QUOTES

"The dogmas of the quiet past are inadequate for the stormy present.....we must think anew and act anew. Fellow citizens, we cannot escape history." -President Abraham Lincoln

"We must scrupulously guard the civil rights and civil liberties of all citizens, whatever their background. We must remember that any oppression, any injustice, any hatred, is a wedge designed to attack our civilization." -President Franklin Delano Roosevelt; first U.S. President who was a wheelchair user

"We will not tolerate another generation of young people with disabilities going through segregated education, segregated society, being dependent on their parents and public aid. We can make a difference in their future. If people with disabilities have a future, then everyone in our society will have a future."

> -Ed Roberts, founding member of the Center for Independent Living, Berkeley, California

"The most pathetic person in the world is someone who has sight but has no vision." - Helen Keller

"What is the difference between an obstacle and an opportunity? Our attitude toward it. Every opportunity has a difficulty and every difficulty has an opportunity." - *J. Sidlow Baxter*

A FEW MORE THOUGHTS ON LEADERSHIP

WHAT IS LEADERSHIP?

Leadership is the ability to analyze one's own strengths and weaknesses, set personal and vocational goals and have the self-esteem to carry them out. It includes the ability to identify community resources and use them, not only to live independently, but also to establish support networks to participate in community life and affect positive, social change.

A key part of YLF focuses on learning to appreciate the experience of disability, disability culture and disability rights. But developing an understanding of these issues is only a first step in our own self-awareness and leadership development. The most effective disability community leaders also have an appreciation of the issues affecting the civil rights of all humanity and a concern to make the world a better place for all.

WHAT IS YOUTH DEVELOPMENT?

Leadership is an important part in the overall development of all people, including youth with disabilities. **Youth development** is a process which prepares young people to meet the challenges of adolescence and adulthood through a coordinated, progressive series of activities and experiences which help them to become socially, morally, emotionally, physically, and cognitively competent. When we talk about youth leadership and youth development, we talk about it positively, meaning we don't focus on what we're lacking, but instead on what kinds of opportunities, activities, and experiences can help build a young person up.

WHAT IS MENTORING?

Mentoring is a term you will hear a lot at this forum. There's a formal YLF Luncheon and events and activities designed to help you make connections with potential mentors. But in order to get the most out of these relationships, it helps to know what it means. **Mentoring** is a trusting relationship, formalized into a program of structured activities, which brings young people together with caring individuals who offer guidance, support, and encouragement aimed at developing the competence and character of the mentee. Remember, this doesn't mean that the only people who can be mentors are adults or professionals. You can be a mentor to your peers, folks younger than you, or even people older than you based on your own personal development and experiences.

JOIN THE CALIFORNIA Youth Leadership Forum ALUMNI!

The mission of the California Youth Leadership Forum Alumni (YLFA) is to organize alumni of the California YLF for Students with Disabilities to advocate, organize, and further the rights of youth with disabilities in California and ensure the continuation of the California YLF. The organization takes an active role in the planning and production of the YLF program in partnership with other organizations and state agency partners who support the program's purpose. All aspects of this organization will be fully accessible to all its members and allies.

All members of the California YLFA must be alumni of the California YLF.

Once you complete the week long forum, you become alumni. To become active alumni, please follow us on Facebook. Search "California YLF."

Please be sure to introduce yourself on our wall. Remember to include your full name, the year you attended YLF and your thoughts about your experiences at the California YLF.

California Youth Leadership Forum Alumni Cynthia Cadet – Alumni 1998 <u>cynthiacadet@hotmail.com</u> (619) 454-3004

Rosie McDonnell-Horita – Alumni 2010 <u>rmcdonnell22@yahoo.com</u> (760) 822-3555

Alex Mentkowski – Alumni 2006 Alexm16@gmail.com (720) 317-7387

YLF 2013 PROJECT SPONSORS

We gratefully acknowledge the financial support of these foundations, corporations, companies, and agencies. Without this support, we could not produce our Youth Leadership Forum (YLF). And we extend our gratitude to the hundreds of YLF volunteers who give the critical, generous gift of their time, commitment, and caring to produce our 2013 YLF.

FOUNDING SPONSORS

AT&T (Formerly Pacific Bell) Wells Fargo IBM Corporation The California Endowment TRW Santa Rosa Rotary Club Friends of Californians with Disabilities, Inc.

PRIVATE SPONSORS

Wells Fargo Molina Healthcare of California Lockheed Martin Corporation Sutter Health Foundation ADECCO Center for Excellence in Developmental Disabilities, UC Davis M.I.N.D. Institute Inland Empire Health Plan Consumers Attorneys Public Interest Foundation Californians for Disability Rights, Inc. Mission San Rafael Rotary Club Marin Center for Independent Living California YLF Alumni Alliance California Foundation for Independent Living Centers, Inc. Friends of Californians with Disabilities, Inc.

GOVERNMENT PARTNERS

California Committee on Employment of People with Disabilities California Employment Development Department California Department of Rehabilitation California Department of Education California State Independent Living Council California State Council on Developmental Disabilities California Workforce Investment Board California Department of Developmental Services Disability Advisory Committee, Department of Consumer Affairs Disability Advisory Committee, Contractor's State License Board California Health Incentives Improvement Project

2013 LEADERSHIP TEAM

California Committee on Employment of People with Disabilities California Department of Rehabilitation California Employment Development Department California Foundation for Independent Living Centers California Health Incentives Improvement Project California YLF Alumni Friends of Californians with Disabilities, Inc.

PEOPLE I WOULD LIKE TO KEEP IN TOUCH WITH:

NAME	TELEPHONE (Area Code) (Number)	<u>E-MAIL</u>	<u>ADDRESS</u>



Edmund G. Brown, Jr.

Governor State Of California

Marty Morgenstern

Secretary Labor and Workforce Development Agency

Diana S. Dooley

Secretary Health and Human Services Agency

Tri-Chairs Michelle Alford-Williams, Rachel Stewart, and La Juana Thompson

2013 Youth Leadership Forum Steering Committee