A Learning Circle On
Disability and Diversity: Serving Those Who Are Underserved
December 11, 2007
9:00 AM - 5:00 PM
Preservation Park, Ginn House
660 13th Street (in Preservation Park)
Oakland, California

Overview
Twenty-five people attended a day-long learning circle on Disability and Diversity: Serving Those Who Are Underserved organized by the staff of the California Foundation of Independent Living Centers and facilitated by staff of the Leadership Learning Community. A list of those who attended with contact information may be found in Attachment A. The purpose of the meeting was to engage providers, consumers, advocates, and disability professionals in a day-long inquiry to deepen understanding about why some people with disabilities are underserved and what can be done to improve utilization of services by all people with disabilities.

Meeting Objectives
The meeting had the following objectives:
• Share personal experiences about the successes and challenges of trying to utilize services and/or improve outreach and use of services to those who are underserved
• Clarify who are those who are underserved in our communities
• Identify organizational, community, and policy-level barriers to providing more inclusive services
• Envision what centers look like that reach and serve diverse populations and how to create them
• Experience the power of peer learning to solve problems

Assessing Our Own Efforts to Increase the Diversity of Who We Serve
Participants were asked to rate their own efforts to increase services to diverse populations. Groups gave themselves the following names and shared their advice and frustrations.

“Hope for More” (Numbers from 3-5)
• Advice: Working with labor unions brings in more diversity
• Frustration: Lack of funding

“Empowerment” (All sevens)
• Advice: Clarify roles, rights, and responsibilities; Building communication as the bridge; Training
• Frustration: Attitudes; Lack of communication
“Paradigm Shifters” (Numbers from 5-8)
• Advice: Finding people with right attitudes, openness, learning how to listen; Getting more exposure to different disabilities, cultures
• Frustration: Financial capacity of our organizations

“The Cool Group” (Numbers from 5-8)
• Advice: Looking at the difference between independence and interdependence and the values in our community; Facilitating and gathering rather than providing services
• Frustration: Ignorance, attitudes

How to Use the Continuum Exercise
The Continuum Exercise is used to raise awareness among people about what contributes to and interferes with success. The exercise asks people to imagine a continuum where 10 is being highly successful and 1 is fraught with frustrations and obstacles to success. The facilitator brainstorms 10 and 1 to give people a “feel” for the continuum. Each person is asked to think about themselves, their organizations (or some other context) and assign a number that captures where they are on the continuum. Participants arrange themselves in a line by their numbers and then cluster in groups of 4-5. Each group is asked to share why they chose the number they did with others in the group. The group then gives themselves a name and comes up with one piece of advice and one frustration to share with the larger group.

Storytelling
An excerpt from The Spirit Catches You and You Fall Down was read aloud.

Neil Ernst and Peggy Philip were shocked to discover quarter-sized round lesions on the abdomens and arms of some of their pediatric patients. They looked like burns. Some of the lesions had healed and others were still crusty, suggesting that the skin had been traumatized on more than one occasion. Neil and Peggy immediately called the Child Protective Services office to report that they had identified several cases of child abuse. Before the cases were prosecuted, they learned from a San Francisco doctor that the lesions were the result of dermal treatments – rubbing the skin with coins or igniting alcohol-soaked cotton under a tiny cup to create a vacuum – that were common among several Asian ethnic groups, and that they were a “traditional healing art,” not a form of abuse. Dan Murphy remembers that when he was a resident, he heard a story about a Hmong father in Fresno who was sent to jail after black marks were discovered on his
child’s chest by an elementary school teacher. The father hanged himself in his cell. The story is probably apocryphal (though it is still in wide circulation), but Dan and the other doctors believed it, and they were shaken to realize how high the stakes could be if they made a tactical error in dealing with the Hmong. (pages 64-65)

Participants were asked to think of a time when they were frustrated in trying to utilize services or improve outreach and availability of services to those who are underserved and how they responded to or dealt with the issues they were facing. Each person shared their story in groups of three.

### How To Use Storytelling

Storytelling gives people an opportunity to share an experience that has meaning for them personally around some theme. The storyteller paints a picture using words to help people understand something important or meaningful to them. Through storytelling people make connections with one another. Each person is asked to take a minute or two to think about story and jot down a few notes if they wish. In groups of 2-4, each person takes 3-5 minutes to share their story while the others in the group listen. Participants are asked to listen for the common and different themes in their stories. After sharing their stories in small groups, participants come back together in the larger group to surface the themes that they heard.

### Story Themes

The following themes emerged from the stories that people told each other:

**Bias and ignorance**
- Ignorance often manifests along different lines of race, disability, geography
- When people do not speak English, they are often treated differently.
- Children were taken from a home because of a misunderstanding about the food that their family served them
- Family decision-making patterns differ among different ethnic groups

**Power and money**
- Gatekeepers block access
- Who gets to decide what it means to be independent – the person with a disability or the provider? There are cultural differences.
- Lack of available resources

**Taking action**
- People were willing to call public attention to issues by coming together and raising awareness
We can’t not act! e.g. in one meeting, the interpreter was not voicing for a deaf person who was testifying and no one informed him – we have to insist that this not happen

Roving Conversations
Participants were asked to brainstorm answers to four questions:

- Who is being underserved in our communities?
- What’s the cost of not adequately serving the entirety of our communities?
- What are the internal barriers (language, staff cultural competency) and external barriers (policy, funding, etc.) that perpetuate under-utilization of services by underserved populations?
- What are promising practices you have tried or heard about from others that improve the diversity of who is served?

In what follows we have compiled and categorized your responses. What themes do you notice?

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How To Use Roving Conversations

Roving Conversations is a process to help a group gather multiple perspectives on a set of key questions. The questions are posted on flipcharts and the group is divided up so that there is a small group (3-6 people) that starts with each question. Each question has a host-recorder that stays with the flipchart as the groups rotate to each flipchart. Groups are given 10-20 minutes at each question (often later groups require less time because there is a lot of information already present). Groups can add to or raise questions about previous answers to the question. At the end we have found that there is great value in having someone type up and develop categories for responses to the questions. This helps the group understand better the work that they did together.

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Question 1: Who is being underserved in our communities?

Disability

- People with cognitive and psychiatric disabilities
- Learning disabilities
- Autism
- Functionally illiterate
- Families of children with disabilities
- Those who don't identify with their disability
- People with hidden disabilities
- Deaf and hard of hearing
Visually impaired
- Traumatic brain injury
- Dual diagnosis

**Race and Ethnicity**
- Latino
- Immigrants (documented and undocumented)
- Non-English speakers

**Gender and Sexuality**
- LGBT
- “Section 21” – addresses race and ethnicity – needs to be more representative of more underserved populations, i.e. LGBT and other diverse groups
- Battered women/survivors of domestic violence

**Occupation**
- Veterans
- Agricultural farm workers
- Working poor

**Age**
- Youth
- Teens and seniors
- Teens
- Transition age youth

**Location**
- People who live in unincorporated areas
- American Indian country (reservation and rural)
- Rural communities
- Areas with lack of public transportation system
- Lack of accessible/reliable transit
- “Hidden” communities
- People in institutions
- Homeless, transient, without permanent address
- Isolated individuals
- Those not digitally wired
- Prison population

**System**
- Systems that provide services to people with disabilities

**Question 2:** What’s the cost of not adequately serving the entirety of our communities?

**Personal**
- More alienated teenagers with rifles
- Alienation and isolation by people who are not reached
- Individuals die inside from emotional pain
- Everything negative is exacerbated for the individual and everyone in their lives

**Organizational**
- Staff retention (high turnover)
- Key is “adequately.” You burn out staff and community if you cannot deliver on your promise. e.g. translate materials without bilingual staff
- Not truly meeting our mission and vision
- Bureaucracy drives people away, e.g. as a consumer, I get asked the same question five times

**Community**
- We lose out when people can’t come to us – we need to go to them and build trust
- Wider circle of people who could benefit don’t
- Entitlement costs increase
- Silos – we perpetuate silos if we are not serving the entire community
- The community is not empowered
- Risk limiting constructive venues for change

**Cultural**
- Cultures wiped out by alcoholism and loss of hope, drugs
- Multi-generational dependence
- The next generation will see our service approach as a model. If we don’t value the entire community, the next generation won’t
- When we are not out there, we are not changing stereotypes
- If we don’t learn from history, we will repeat it

**Attitudes**
- Stigma gets perpetuated as does institutionalization and dependence vs. interdependence
- Ignorant that we would not serve everyone – disability does not discriminate
- Paradigm shift – we will lose out if we don’t embrace change. We are a world community

**Leadership**
- Missed opportunities for new leaders and alliances, e.g. Kyoto accords are making a profit from making change
- Lose valuable perspectives
- People bring resources
- Need to empower and educate by going out – people can be afraid to approach us for services. Nurture understanding and skills.
- We will go backwards – weakening ADA – lack of new leaders
- Risk of complacency and regression – don’t know struggles of the 80’s – need to mentor youth – e.g. racial discriminations/lynching
Economic
- More people in the streets asking for $
- Lack of $ for both rent and food
- If we don’t provide services, people with disabilities will not become less dependent
- Weakened economically and as a society – country greater divide of the haves and have-nots
- We lose economically when people who could work don’t have the opportunity
- Want people to be better off with more opportunities, especially youth

Services and systems
- If you don’t have systems for caregiving, it is hard on the entire family
- Less services, e.g. coming out from a 72 hour hold – regression of services
- Indian country – no services
- People have to make very choices about health care
- Difference in SSDI and SSI – sexism
- E.g. Problems (domestic violence) not addressed

Outcomes
- Social Security and health care problems
- More people go into hospitals and unable to live independently in community
- More homeless
- Cost in human life when people don’t receive services

Question 3: What are the internal barriers (language, staff cultural competency) and external barriers (policy, funding, etc.) that perpetuate under-utilization of services by underserved populations?

Internal Barriers

Attitudes
- Fear
- Lack of value for other cultures and understanding of how to/communication across cultures
- Not taking time to learn about other people
- Discrimination that is unexamined

Staffing
- Not enough staff
- Lack of staff training
- Staff may not want to take on something new
- Don’t even have capacity to serve all people who are already coming in your door
Language and Communication
- Lack of staff communication skills to serve certain populations (e.g. ASL, Spanish)
- Different nonverbal norms (e.g. eye contact, gestures) across cultures and generations

Leadership
- Lack of cross-training
- Balancing time and dollars to train staff vs. provide services
- Lack of leadership – board, management – and depth in organizations as to how to better serve community

Structural
- Disability hierarchy
- No place to release stress
- Lack of diverse representation within management and decision makers
- Lack of accessibility
- Lack of communication/conversation between staff in organization (vertical communication)

External Barriers

Attitudes
- Potential consumer may not view self as having a disability
- Hopelessness/despair/high stress
- American Indians don’t trust State, Federal government systems
- People who are excluded/discriminated against in healthcare (i.e. LGBT, size, appearance) – may opt out
- Minimum standards? (who decides) “ADA not good enough . . .”
- Only doing “compliance”
- Labeling people (“you should label jars, not people)
- Labels (consumers, clients) set up a service hierarchy
- Ignoring communities
- Negative attitudes

Awareness
- Not knowing where to go to get services
- Lack of knowledge about underserved
- Not understanding “white privilege”

Resources
- Lack of time
- Lack of assistive technology
- Lack of interpreters
- Lack of funding
Partnerships
- Not enough partnerships between State systems and urban Indian centers
- Lack of collaboration of organizations that serve the underserved

Systems
- Systems make it very hard to enter and receive services
- All systems – regulations, paperwork – take away from serving people

Question 4: What are promising practices you have tried or heard about from others that improve the diversity of who is served?

Conceptualizing Diversity
- Broaden how we define disability

Raising Awareness
- Using fun exercises to raise awareness
- “Infiltrate” other organizations so that you will learn about diverse communities and cultures, and they will learn about disability services
- Facilitate group identity conversations and then convene people altogether to share needs and what they have learned; facilitation is a key skill, getting an understanding subtly
- Finding and sharing how we have been oppressed
- Disability awareness exercises – take on someone’s disability to learn from it – role playing – people feel the oppression and ignorance
- Using street theater
- Plays to let people know what their rights are
- Start young so kids with disabilities hear that they can do what others without disabilities do
- Speaking up and letting people know because the unknown is scary
- Raise awareness about disability in local politics, get more involved to create better policies

Creating a Welcoming and Inclusive Organization
- Staff and board should look like your community
- Office being welcoming to community
- Posting our hours in three languages
- Translating materials
- Restroom sign in four languages
- “The frog” that speaks to alert the visually impaired about the entrance
- Etiquette of how to offer help
- Dedicated phone lines in different languages
- Having staff people who are from that culture who are capable of meeting people where they are

Collaboration and movement building
o Collaborating with agencies so services aren’t duplicated
o Create connections, synergy and alliances
o Inter-agency collaboratives – breaking down silos – Santa Clara County partnering with Council on Aging – CIFLC-CAPA
o Coalitions working on a common purpose
o Modeling collaboration/inclusion
o Self-help movements, care giving, peer support and networks

Developing Leadership
o Specialized training that give people opportunities to move up
o Leadership development
o Recognize diversity within staff and building on what you have
o Teach everyone how to accommodate different disabilities so that people with disabilities are not always asked to make requests for accommodation
o Train people to be receptive and non-judgmental (brokers of information), provide information about how to locate help in a community
o Provide mentoring
o Create links so that institutional memory (e.g., information/knowledge) gets shared in an uninterrupted way
o Create an environment that gives people who leave employment at CILs an opportunity to participate

Changing Policies and Outmoded Practices
o As a result of legal changes there are now 25 SILCs that have Native representation
o Get rid of outdated information – e.g. drivers license interpretation system>videos
o Create a best practice curriculum

Technology and Funding
o Assistive technology
o Corporate philanthropy that supports diversity (i.e. Intel, Wells Fargo)

Visioning
The group was led through the following visioning exercise.
• Imagine a world five years from now where everyone you meet, who has a disability in your community, has the support and services they need to lead a quality life no matter what their disability, no matter what their race.
• Everywhere you look you see the manifestations of a community that supports and serves every person with a disability.
• What do you see?
• What do you hear?
• What are you feeling?
• How are people with disabilities connecting to the supports and services they need?
• How are people reaching out and providing supports and services?
• What has fundamentally changed?

How To Use A Visioning Exercise
Visioning is used to help people to imagine with no constraints from fears, doubts or notions of feasibility, what it you really want and not just what you are willing to settle for. Visioning is powerful for two reasons. First, when you let yourself vision, sweeping all limiting considerations away, you're often surprised by what you see. And second, having seen that, you find opportunities, make decisions, and venture forth in a much more clear and purposeful way. People are asked to sit comfortably, close their eyes if they feel comfortable doing so, and take 3 centering breaths. Each statement is read slowly leaving several breaths for people to visualize. People are asked to open their eyes and write for 3 minutes about their vision. (Have people prepare paper and pencil before the visioning begins.) Each person shares his/her vision with one other person for 3-5 minutes apiece. In the large group people are asked to share ahas, surprises, insights.

Elements of Visions from the Group

How We Relate to Each Other
- Open mindedness
- Talking circles -- everyone included equally
- “My Space”

What the Outcomes Are
- Everyone is working and happy (Sesame Street)
- Changes in social security
- Universal healthcare and stipend
- Better laws and policies

World Cafe

How To Use the World Cafe
The World Café is used to help small groups have deep conversations around questions that matter to their life, work or community; and to connect those conversations with one another by rotating among tables. Café tables are set with tablecloths, flowers, paper, and markers. A question is posed for table top conversation. After 20 minutes, people rotate with one person staying at the table to host the next group. A second round of conversation
is held on the same question. Guests are encouraged to link and connect ideas coming from their previous table conversations. A third round is held using a new question to help the group deepen the exploration. After completing three rounds, participants share any patterns or themes that emerged from their conversations.

Good introductory facilitation resources for the World Cafe may be found in Café to Go www.theworldcafe.com/articles/cafetogo.pdf

World Café Debrief
The group surfaced the following themes:

Youth
- Mentor and involve youth
- Takes youth, energy and passion to get movements engaged
- We need to get people on the board and have new EDs who are younger-maybe interns
- More elders to listen and help envision (and let new visions emerge)

Outreach and collaboration
- Outreach – throw out flyers – go out in small groups – build trust
- Establish meaningful collaborations with organizations that know their folks will receive culturally appropriate services
- Word of mouth, repetition, being there – community and consumer involvement. Find common interest – be persistent – open door
- Centers in the community – even in bad neighborhoods

Diversity and organizations
- Diversity of center staff
- Accountability in diversity plans, but more so to consumers. Ask questions for consumer satisfaction – specifically about diversity.

Open Space
Open space was used in the late afternoon to delve more deeply into the following topics:
- Youth involvement/engagement
- Finding and utilizing interns
- Where do we need to grow personally; what risks do we need to take?
- Diversity Leadership Institute

How To Use Open Space
Open space is a meeting methodology that gives participants responsibility for defining the agenda around themes or questions they care most about addressing. It is a powerful way to bring people together to search for solutions to complex issues. Participants are asked to contribute topics for
discussion. After announcing the topic, they pick a place to meet and a
starting time. There are several rules of Open Space:
1. The people who show up are the one’s who are meant to do the work.
2. The law of mobility: Move if you are not where you feel you have
something to contribute or learn
3. If you are the host, let people know where you will be and when your
work is done.

Good introductory facilitation resources for Open Space may be found at
http://www.openspaceworld.org/cgi/wiki.cgi?FacilitatorResources

Key Points from Open Space Discussions

The Diversity Leadership Institute
Recruitment and Selection
• Consider inviting other disability-serving organizations besides CILs;
invite more than one person from the organization to come
• Need to think about identifying and training “evangelists” (e.g., people
who can go out and promote the vision within their organizations and
in their communities
• First target audience needs to be other CILs
• Create an easier application
• Market the program better to EDs (e.g., we are creating a resource for
you that is going to make your job easier)
• Program managers would be a good target audience

Setting expectations
• Make sure that clear expectations get communicated to the Executive
Directors. (Some EDs did not include DLI participants in their diversity
planning efforts.)
• Get together with DOR in advance to find out what they want so
people can be trained to fulfill that (e.g., it would have been helpful in
advance to know that DOR was asking centers to develop diversity
plans)
• Participants need a clear goal for their projects.
• How do we balance adding one more responsibility to someone’s plate?

Focus of training and facilitation
• DLI facilitator needs to know where the rubber hits the road in our
centers
• More training to help EDs create leadership opportunities for their staff
• Pay more attention to how people will take what they have learned
during the DLI back to their centers (e.g., sharing it with others)

Administration
• Increase support for CFILC to support this project
**Evaluation**

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