

State Council on Developmental Disabilities
Community Outreach &
Regional Advisory Committee Meeting

Wednesday, November 28, 2018

Networking 6:30PM- 7:00PM, Meeting 7:00PM to 9:00PM

Alameda County Office of Education

313 West Winton Ave, Room 142, Hayward, CA

Collaboration is key! We invite members of the community to share input, issues and concerns. All are welcome.

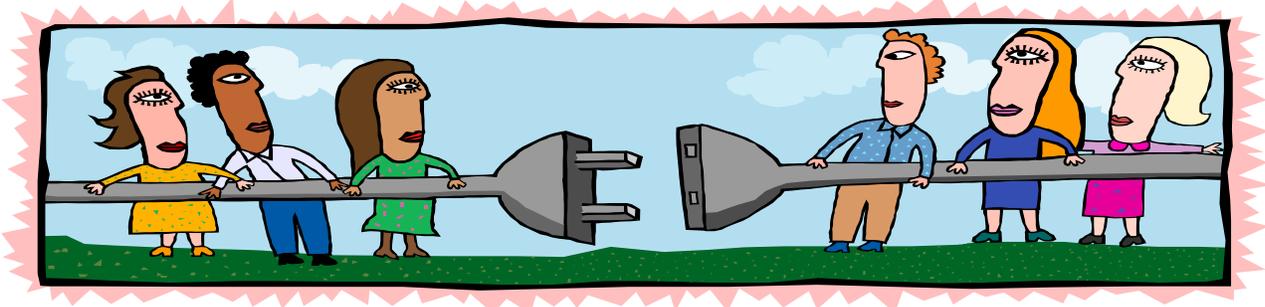
Featured this meeting:

Updates & current projects from the Regional Advisory Committee Members, the Bay Area Regional Office, regional efforts to reduce healthcare and education disparity, and more!

For Information: State Council on Developmental Disabilities Bay Area Regional Office
510-286-0439 or bayarea@scdd.ca.gov
1515 Clay St. Suite 300 Oakland, CA 94612

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STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

BAY AREA REGIONAL ADVISORY COMMITTEE (RAC) MEETING & COMMUNITY OUTREACH

NOTICE & AGENDA*



Date Wednesday, November 28, 2018



Time Networking 6:30pm – 7:00p, Meeting 7:00pm – 9:00pm



Location Alameda County Office of Education
313 West Winton Ave, Room 142
Hayward, CA

This Regional Advisory Committee Notice & Agenda is posted: <http://www.scdd.ca.gov/bayarea/>

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Please refrain from wearing scented products at this meeting, thank you.



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Phone. 510.286.0439 Fax. 510.286.4397 www.scdd.ca.gov



7:00p Call to Order

Introductions / Establishment of Quorum

Garcia



7:10p Approval of the meeting minutes of 10.03.2018

Garcia



7:15p Public Comment

An invitation to provide the public an opportunity to comment and/or present information to the Committee on **any matter that is not on the agenda**. Each public member is afforded up to 3 minutes to speak. Written requests will be considered first. The Committee will provide a public comment period not to exceed 5 minutes total for all public comments prior to action on any agenda item.



**7:25p Report from Regional Advisory Committee Members
& from Council Member Lau**

Garcia

Hear updates from RAC members on their regional and statewide advocacy work, and priorities. Here updates about the Council's work, and highlights from the last Council Meeting. Learn about themes and strategies in increasing education parity work, from RAC Member and Co-Chair Garcia.



8:10p Overview of the UCSF Office of Developmental Primary Care

Learn about the projects and tools developed regionally to increase healthcare awareness, access, and parity for patients with I/DD and other disabilities. Presenters: Jo Cummins, Program Coordinator; and Patricia Mejía, Program Manager/Community Liaison, CART Services, both from the University of California, San Francisco, Office of Developmental Primary Care, Department of Family & Community Medicine



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8:25p Report from SCDD Bay Area Regional Office

Nicholau, Usac

Review highlights and themes from the last quarter of the regional office's recent State Plan work. Hear and see an overview of the how the Bay Area Regional Office supports regional self-advocacy organizations like People First, and statewide orgs like SSAN.



8:35p Reports

Garcia

- Regional Center Reports
- County DD Council Reports
- People First Report



8:55p Other Announcements & Agenda Items for Future Meetings

An opportunity of members of the community to bring up ideas, needs, issues and concerns



9:00p Meeting Adjourned

Garcia

***All times indicated and the order of business are approximate and subject to change. Any agenda items have the potential to be brought for a vote.**



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**State Council on Developmental Disabilities
Bay Area Regional Advisory Committee Meeting
October 3, 2018 Minutes **DRAFT****

Location: Marin County – Marin Co. Office of Education, 1111 Las Gallinas Ave, San Rafael

Committee Members Present: Kristen Anderson (FA), Sascha Bittner (SA), Francisco Garcia (FA), Elizabeth Grigsby (SA), John Marble (SA), Janet Miller (FA), Julie Neward (FA), Pam Perls (FA), Kate Rauch (FA),

Committee Members by Phone: Nicole Adler (SA), Christina Lasson (SA), Dianne Millner (FA), Jude Stern (FA)

Committee Members Absent: Regina Woodliff (SA),

Guests Present: Jerry Grace (Northern Alameda People First (NAPF)), Eric Zigman (GGRC), Lisa Kleinbub (Regional Center of the East Bay (RCEB)), Will Sanford (Futures Explored), Abby Yim (Integrated Community Services), Barbara Wilson (FA), Michelle Garcilazo (Marin County Field Representative for Congressman Jared Huffman), Barbara Rosen (FA), Beatrice Rauch (SA)

Guests by Phone: Debra Adler (FA), Deborah Pearl (FA), Sara Desumala (SA - People First, SF), Patrick MacKay (SA),

Staff: Sheraden Nicholau, Ron Usac, Angel Marshall, and Valerie Buell

State Council Members Absent: Francis Lau (FA)

7:06p Call to order/Introductions/Establishment of Quorum

7:11p Approval of the meeting minutes of 6/27/2018

Moved by: Francisco Garcia

Seconded by: Kristen Anderson

Vote: All Ayes

7:13p Public Comments:

Barbara Rosen expressed concern that the Supported Living Services (SLS) regulation on background checks for paid staff, volunteers, and contractors is still discretionary, pointed out the vulnerability of this community, and asked how many complaints it will take to make change and if the committee will ask the legislature to update the regulation to require background checks.

Michelle Garcilazo from Congressman Huffman's office introduced herself to the committee as both a parent of a child with IEP needs, and that she is an immigration rights specialist.

Patrick McKay shared he may not be able to attend these meetings anymore.

Sascha Bittner announced that because we have seen an increase in committee members and in members of the public wishing to join RAC meetings via teleconference, we can look to Bagley-Keen guidelines regarding calling in to the meeting, making comments, or voting. Members of the committee will need to notify the Bay Area Office of their designated public call-in site(s) before the deadline, more than 10-days before the RAC meeting. A designated public call-in site needs to be a public site, meaning the location address(es) will be posted on the RAC Agenda, sent 10 days in advance, so that members of the public are notified of the site and can convene at the designated public call in site(s), should they choose. However, if RAC member is not able to



participate but just wants to listen in, they may call in from anywhere -- but would not be able to make comments as a RAC member, or vote.

Will Sanford said he believes that rule would only apply to a RAC member regarding voting, and not to a member of the general public making a public comment, and suggested that the rules on Bagley-Keen be reviewed for this verification.

Sascha will confirm guidelines and will provide this for the next RAC meeting.

7:27p Report from Regional Advisory Committee Members

Each Regional Advisory Committee member in attendance gave a report on the advocacy work that member has been doing in the community over the last year. Reports from Francis Lau and Dianne Millner were read aloud by Bay Area Office Staff members Angel Marshall and Valerie Buell.

Some activities/work reported was:

- Work on the Local Self-Determination Advisory Committee for GGRC's catchment area, including pre-enrollment meetings
- Work on the Local Self-Determination Advisory Committee for RCEB's catchment area, including pre-enrollment meetings
- Work on the Golden Gate Self-Advocacy Conference
- Serving on the Community Integrated Services Board of Directors
- Running a non-profit that offers recreational programs for any age up to 22
- Operating a program called Neurodiversity Pathways that trains people with autism to mainstream into competitive positions and providing companies with training to hire, train, and retain autistic employees
- Spoke in favor of Bill SB 820; the Settlements Agreements: Confidentiality bill
- Spoke at the National Sexual Assault Conference in Anaheim
- Work as an advocate for Disability Rights of California
- Work as a freelance writer, writing about Developmental Disability issues
- Help launch Bridge to Success, a Contra Costa County employment program
- Work on the Contra Costa Developmental Disability Council (CCDDC)
- Work on the East Bay Legislative Coalition and the Forensic Sub Committee of the Health and Wellness Committee
- Work in the Hispanic Community to inform and engage other families, to let them know what services are available
- Work in a core group on Person-Centered Thinking training, and training providers
- Camp Counselor at Camp Pals for People with Down Syndrome
- Serving as President for two chapters of People First
- Attending meetings on the rapid developments in how Artificial Intelligence (AI) is being used in the health care field
- Work on the CalABLE program that is scheduled to be launched in the middle of December 2018

Upcoming Activities mentioned were:

- The Grand opening celebration at the Summersville Towne Center mall in Antioch will unveil the first public adult changing table in a shopping mall in the United States
- The first LGTB Autistic/Neurodiversity meet up in San Francisco is this Saturday
- ASCEND and San Francisco State University is hosting a Free Conference called Autism in the Media on Saturday October 20th 9:00 AM to 4:30 PM

8:06p Reports:

- **Bay Area Office:** Sheraden gave an overview of the Bay Area Office Quarterly Overview, the Quality Assessment Project, the Client's Rights Advocate and Volunteer Advocacy Services (VAS), the recent partnership with the Job Accommodation Network & IBM on an increasing disability employment event, and invited RAC members and guests to let the office know if they want to participate in any of the trainings and events hosted by the office.
- **Regional Center Reports:**
 - Eric Zigman/GGRC reported:
 - GGRC will roll out an electronic newsletter, to be sent out 4 times a year
 - An overview of persons served by GGRC
 - Shared info about a recent video created to illustrate and educate about the move from the Developmental Centers, called "Chris's Story". Noted that SCDD's Angel Marshall was involved in the project and interviewed a person-served named Chris. The video is waiting for final approval for release
 - GGRC has one individual left to transition out of the Developmental Center
 - This Saturday in Redwood City: Congreso at Fair Oaks community center from 9:15am to 3:30pm, hosted in the GGRC
 - Lisa Kleinbub/RCEB reported:
 - RCEB is working on a lot of similar things to GGRC, they still have 19 people to transition out of the Developmental Center, as some of the new homes being constructed are experiencing construction delay
 - An update on the Northern California homes for the Safety Net, providing crisis services for people who need additional support than what is offered in their community
 - October 13th is the Global Village Conference, which will be held in multiple Asian languages
 - Making a renewed effort to look at risk management and how to support the more vulnerable people-served, and how to best assess needs.
- **Developmental Disabilities Council:**
 - Ron Usac gave the Contra Costa DD Council report sent to him by Vi Ibarra:
 - October 4th is the 5th Annual Disability and Access and Functional Needs Forum
 - Partnering with the East Bay Legislative Coalition (EBLC) and presenting a Disability Education Forum for Assembly District 16 candidates to answer questions about issues specifically affecting individuals with Intellectual/Developmental Disabilities
 - Conference on Saturday Dec 8th "Let's Keep Learning" is coming up
- **People First:**
 - Christina Lasson gave the reports for Bay Area People First and Northern Alameda People First report:
 - In recent meetings, they talked about CalABLE, Self-Determination and Employment
 - They are planning the Carlos Quintong Self-Advocacy Celebration coming up on October 19th
 - Jerry Grace reported to the conference in Sacramento and shared the donation request letter from People First for the Carlos Quintong Self-Advocacy Celebration

9:07 Other Announcements:

Will Sanford announced Assemblymember Jim Frasier will hold a town hall meeting / listening session on October 24th from 5:30pm -7pm at Concord's Council chambers, including hearing about transportation and housing needs. There was a Disability Forum for the two candidates running for District 15, Assemblymember Tony Thurmond's seat, which was taped and is available for people to watch.

Patrick McKay was awarded with the Self-Advocate of the Year Award at the Golden Gate Self-Advocacy Conference in September.



9:10p Meeting Adjourned

*Documents referenced were in the RAC packets and in the handouts at the meeting for guests. They can also be found on the website www.scdd.ca.gov/bayarea.htm



Bay Area Regional Office Quarterly Overview, Q4 FY 2017-2018

Q4 Totals: **Constituents Engaged in Bay Area Region through Events, Trainings, Activities**

- 462 Self-Advocates
- 706 Professionals, Members of the Public
- 319 Family-Advocates
- 106 Additional Constituents provided with Technical Assistance
- **1,593 TOTAL Individuals Directly Impacted**

Q4 Totals: **National Core Indicators & Movers Longitudinal Study Projects**

- **145** Interviewed for National Core Indicators Study
- **62** Interviews for Movers Longitudinal Study
- **207 TOTAL Engaged for These Projects**

Q4 Totals: **A Few Highlights...**

- **26,455** emails sent re. trainings, events, legislation, rights, & opportunities for regional constituents, their families and support teams
- Provided trainings & presentations on rights, policy, & advocacy for self-advocacy groups, family-advocacy groups, provider agencies, regional centers, school districts, at resource fairs & transition fairs across region
- Training for Kaiser Permanente Northern CA Genetics Multi-Specialty Care Team
- Marin Student Accessibility Advisory Committee
- People First Language & Ableism Trainings for San Mateo Co Departments
- Forensics Workgroup & Crisis Stabilization Unit Workgroup, Alameda County
- Person-Centered Thinking/ PCP Coaches & Leaders Workgroup
- Human Rights & Civil Rights Training for People
- East Bay Employment Task Force
- Facilitation of the Contra Costa Co DD Council Strategic Planning Retreats
- Job Accommodation Network Academy
- SPUR.org Event: What Does Access Really Mean? panelist



U.S. Department of Education Office of Civil Rights

OCR protects the rights of persons with disabilities, including students and parents, under two federal laws in the education context. Section 504 of the Rehabilitation Act of 1973 prohibits discrimination based on disability in any program or activity operated by recipients of federal funds. It states: “No otherwise qualified individual with a disability in the United States...shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance...”

Title II of the Americans with Disabilities Act of 1990 (ADA) prohibits discrimination based on disability by public entities, regardless of whether they receive federal financial assistance. Title II states: “[N]o qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.”

The Reports and Resources lists additional U.S. Department of Education Resources on a variety of ED publications, most available online, that set forth the rights of students and others to be free from discrimination based on race, color, national origin, sex, disability and age. Links include:

[OCR Reports & Resources](#)

[ED Pubs On-Line Ordering System](#)

[Database of ED Publications in ERIC](#)

[ED Legislation, Regulations, and Policy Guidance](#)

[National Center for Education Statistics Electronic Catalog](#)

More information about [ED Publications and Products](#)

[Archived Information](#)

**Frequently Asked
Questions About
Disability - General**

[What are Section 504 and Title II?](#)

Section 504 is a federal law that prohibits any entity that receives

federal financial assistance (such as grants or student loans) from discriminating against persons with disabilities.

Title II of the Americans with Disabilities Act is a federal law that prohibits state and local governments (such as public school districts, public colleges and universities, and public libraries) from discriminating against persons with disabilities.

In general, Section 504 and Title II nondiscrimination standards are the same, and in general, actions that violate Section 504 also violate Title II. However, where Title II requirements exceed Section 504 requirements, public school districts, colleges and universities, and libraries must also comply with the Title II requirements.

What does "person with a disability" mean within the context of Section 504 and Title II?

Person with a disability means a person with a physical or mental impairment that substantially limits a major life activity; has a record of such an impairment; or is regarded as having such an impairment. The determination of whether a student has a physical or mental impairment that substantially limits a major life activity (and therefore has a disability) must be made on a case by case basis. In addition, when determining if someone meets the definition of a disability, the definition must be viewed to provide broad coverage of individuals. For more information about the definition of disability, see [here](#).

Are all school districts, colleges, and universities covered by Section 504 and Title II?

Generally yes. All public school districts are covered by Section 504 and/or Title II – this includes public charter schools and magnet schools. All public colleges and universities are covered by Section 504 and Title II. Virtually all private colleges and universities are also covered by Section 504 because they receive federal financial assistance by participating in federal student aid programs. There are some private schools that do not receive any federal assistance, and Section 504 and Title II do not apply to them.

Are all programs in a school, college, or university covered by Section 504 if any part of it receives federal financial assistance?

Yes. All programs in a school or college are covered by Section 504 if the school district, college, or university receives federal financial assistance. Section 504 covers all the operations of a school or college

that receives financial assistance including academics, extracurricular activities, athletics, and other programs. Section 504 applies to actions of a school or college regardless of where they occur, including those that take place in the facilities of the school, on a school bus, at a class or training program sponsored by the school at another location, or elsewhere off campus.

Do Section 504 and Title II protect only students?

No. Section 504 and Title II protect all persons with disabilities from discrimination, including parents and guardians, students, and employees.

What types of Section 504 and Title II cases does OCR handle?

OCR handles cases of disability discrimination involving a range of issues, such as inaccessible facilities; unequal access to [advanced academic programs](#), [extracurricular athletics](#), and [accessible technology](#); the failure to provide elementary and secondary students a [free appropriate public education \(FAPE\)](#), discriminatory discipline, [the denial to college students of appropriate academic adjustments and auxiliary aids and services](#), [disability harassment](#).

Is there someone at my school who can help answer my Section 504 questions?

Generally, yes. All school districts, colleges, and universities receiving federal financial assistance and employing 15 or more persons must designate at least one employee to coordinate their efforts to comply with and carry out their responsibilities under Section 504. This person is often, though not always, referred to as a *Section 504 coordinator*.

Your school is required to publish your Section 504 coordinator's contact information in your school's notice of nondiscrimination, typically found in any bulletins, announcements, publications, catalogs, application forms, or other recruitment materials. The Section 504 coordinator's contact information should also be prominently posted on your school's website. Section 504 coordinators for public school districts can also be found on OCR's coordinators website at <http://www.ed.gov/civ-rtis-coordinators>.

Frequently Asked Questions About Disability – Accessibility and Services

What is the responsibility of school districts, colleges, and universities under Section 504 or Title II to ensure its program and activities are physically accessible to individuals with disabilities?

School districts, colleges, and universities are required to ensure that students and others with disabilities, including parents, are not denied access to programs or activities because of inaccessible facilities, including academic buildings, walkways, restrooms, athletic facilities, and parking spaces.

The precise requirements schools, colleges, and universities must meet to ensure physical accessibility depends on the date a building (or facility) was initially built (constructed) or altered. For more information about accessibility requirements, please visit www.ada.gov.

Even if a building does not have to be made fully physically accessible because of its age, Section 504 and Title II require that every program or activity of the school district, college, or university be made accessible. A common way this is done is to relocate the program to an accessible portion of the building or to another building that is accessible.

What types of services are required by Section 504 and Title II for students with disabilities in public elementary and secondary schools?

School districts are required to provide each student with a disability any special education and/or related aids and services necessary to ensure the student is receiving a free appropriate public education (FAPE). Examples of aids and services a school district may be required to provide include physical therapy or speech language therapy.

In addition, a school district may need to modify the regular education program in order to provide FAPE. Examples of such modifications include additional time to take tests or a modification to a policy regarding the permitted number of absences in a school year when a student's absences are due to a disability.

More information is available on OCR's webpage addressing [Frequently Asked Questions about FAPE](#).

What types of disability-related services are required by Section 504 and Title II for students with disabilities in colleges and universities?

Colleges and universities are required by Section 504 and Title II to

provide students with disabilities with appropriate academic adjustments and auxiliary aids and services that are necessary to afford an individual with a disability an equal opportunity to participate in the school's program. An example of an academic adjustment is extra time to take a test. Examples of auxiliary aids include notetakers, interpreters, readers, and specialized computer equipment.

Frequently Asked Questions About Disability – Disability Harassment

What is disability harassment?

Disability harassment is unwelcome conduct based on a student's actual or perceived disability. Harassers can be students, school staff, or even someone visiting the school, such as a student or employee from another school. Disability harassment can take many forms, including slurs, taunts, stereotypes, or name-calling, as well as disability-motivated physical threats, attacks, or other hateful conduct.

In addition, at the elementary and secondary school level, bullying or harassment of a student with a disability on *any* basis can result in the denial of FAPE that must be remedied under Section 504. More information about the intersection of bullying and FAPE is available [here](#).

What are the responsibilities of school districts, colleges, and universities under Section 504 and Title II to address disability harassment?

Section 504 and Title II require an educational institution to respond to disability-based harassment that is sufficiently serious to deny or limit a student's ability to participate in or benefit from the recipient's education programs and activities (i.e., creates a hostile environment).

When an educational institution knows or reasonably should know of possible disability harassment, it must take immediate and appropriate steps to investigate or otherwise determine what occurred. If an investigation reveals that the harassment created a hostile environment, the educational institution must take prompt and effective steps reasonably calculated to end the harassment, eliminate the hostile environment, prevent its recurrence, and, as appropriate, remedy its effects.

Note that school districts must also assess the effect of bullying and harassment on a student with a disability even if it was not disability-based harassment and even if it did not create a hostile environment.

More information about the intersection of bullying and FAPE is available [here](#).

How do educational institutions balance their Section 504 and Title II obligations with individuals' First Amendment rights?

OCR has consistently reaffirmed that the Federal civil rights laws it enforces protect students from prohibited discrimination, and are not intended to restrict expressive activities or speech protected under the U.S. Constitution's First Amendment.

The fact that discriminatory harassment involves speech, however, does not relieve the school of its obligation to respond if the speech contributes to a hostile environment. Schools can protect students from such harassment without running afoul of students' and staff First Amendment rights. For instance, in a situation where the First Amendment prohibits a public university from restricting the right of students to express persistent and pervasive derogatory opinions about students with a particular type of disability, the university can instead meet its obligation by, among other steps, communicating a rejection of stereotypical, derogatory opinions and ensuring that competing views are heard. Similarly, educational institutions can establish a campus culture that is welcoming and respectful of the diversity all students and institute campus climate checks to assess the effectiveness of the school's efforts to ensure that it is free from harassment. Schools can also encourage students on all sides of an issue to express disagreement over ideas or beliefs in a respectful manner. Schools should be alert to take more targeted responsive action when speech crosses over into direct threats or actionable speech or conduct.

How does OCR address disability harassment against students?

OCR investigates and resolves allegations that educational institutions that are recipients of federal funds or that are public entities have failed to protect students from harassment based on disability. Where OCR identifies concerns or violations, educational institutions often resolve them with agreements requiring educational institutions to adopt effective anti-harassment policies and procedures, train staff and students, address the incidents in question, and take other steps to restore a nondiscriminatory environment.

In addition to resolving investigations, OCR takes steps to inform schools of their obligation to provide a nondiscriminatory

environment. To see relevant policy guidance relating to disability-based harassment or harassment of students with disabilities, please click [here](#).

OCR's field offices also engage in a variety of technical assistance activities in collaboration with state and local education and law enforcement agencies to encourage educational institutions to improve their anti-harassment policies and procedures and to assist students and their parents to work with schools to enhance the schools' anti-harassment capability.

CA Department of Education

Laws, Regulations, & Policies

Federal and state legislation, laws, regulations, policies, legal advisories, and guidance.

State Laws

[California Special Education Reference \(CASER\)](#)  (Posted 22-Jan-2015)

A word-searchable database of special education-related state and federal statutes and regulations, federal guidance documents, and editions of the Federal Register.

State Policy

[Size And Scope](#) (Updated 30-May-2008)

Of Special Education Local Plan Areas as approved by the State Board of Education

State Guidance

[Official Letters from the California Department of Education, Special Education Division, State Director of Special Education](#) (Updated 21-Aug-2013)

Provides program clarification on procedural and/or implementation issues.

[Special Education Transportation Guidelines](#) (Updated 03-Jul-2017)

Guidelines for use by Individualized Education Program (IEP) Teams when determining required transportation services.

Federal Laws

[Reauthorization of the IDEA 2004](#) (Updated 16-Jun-2011)

Links to important references and resources on the Reauthorization of the Individuals with Disabilities Education Act (IDEA).

Federal Regulations

[Final Part B Regulations of the IDEA](#)  (PDF)

The official copy was published in the Federal Register on August 14, 2006.

Special Education

Information and resources to serve the unique needs of persons with disabilities so that each person will meet or exceed high standards of achievement in academic and nonacademic skills.

[Administration & Support](#)

Activities of special education advisory groups and other related information.

[Announcements & Current Issues](#)

Current and upcoming events, time-sensitive issues, and hot topics.

[Common Core Resources for Special Education](#)

Resources and guidelines on the Common Core State Standards (CCSS) for the Special Education Community.

[Data Collection & Reporting](#)

Searchable databases and software for reporting and retrieving special education related information.

[Equal Opportunity & Access](#)

Discloses the practices of the California Department of Education to ensure equal, fair, and meaningful access to its employment and program services.

[Family Involvement & Partnerships](#)

Resources and support for parents, guardians, and families of children with disabilities.

[Laws, Regulations, & Policies](#)

Federal and state legislation, laws, regulations, policies, legal advisories, and guidance.

[Quality Assurance Process](#)

Resources to improve educational outcomes for students with disabilities while ensuring compliance with state and federal laws and regulations.

[Secondary Transition Planning](#)

Resources and guidelines to assist youth with disabilities as they transition from school to adult life, including education and training, employment and independent living.

[Services & Resources](#)

Programs and services available to students with disabilities, publications, training and technical assistance opportunities, and recruitment resources and materials.



Who We Are

The Office of Developmental Primary Care was developed to build the healthcare system's capacity to serve adolescents and adults with developmental disabilities. We do this through clinical services, training, technical assistance, and information and resources.

Our Vision

All people with a developmental disability have access to health services that maximize their wellness and function.

Visit our website at: <http://odpc.ucsf.edu> to find resources for:
Healthcare Professionals | Self-advocates | Family Members & Caregivers | Researchers



Office of Developmental Primary Care · UCSF Department of Family and Community Medicine
500 Parnassus Avenue, MU-3E, Box 0900 · San Francisco, CA 94143
Tel: (415) 476-4641 · Email: odpc@fcm.ucsf.edu · Website: <http://odpc.ucsf.edu>

Key Findings: Persons with Disabilities as an Unrecognized Health Disparity

Population

The *American Journal of Public Health* published a commentary in its *Framing Health Matters* section focused on the importance of addressing health disparities among people with disabilities in relation to access to health care, health behaviors (such as smoking and physical inactivity), health status (the presence or absence of a long-standing disease like diabetes), and social factors that impact health (such as poverty). This work was the joint effort of disability researchers at the Department of Health and Human Services (including the Centers for Disease Control and Prevention and The National Institutes of Health) and Abt Associates.

[You can read the full article here.](#)

Main findings

The paper summarizes evidence demonstrating that people with disabilities across the lifespan experience health disparities, and provides recommendations in key areas for improving their health.

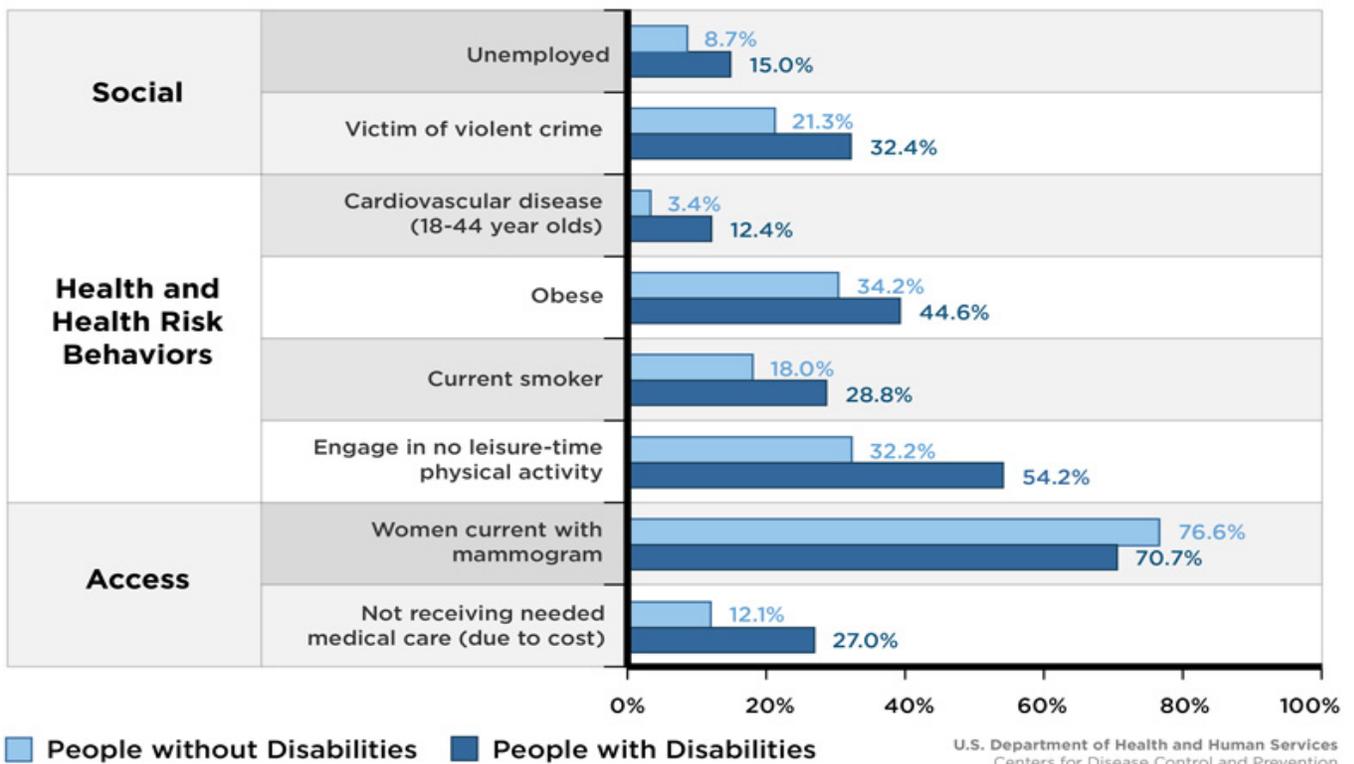
The paper also presents the discussion about disability and health in a historical context, illustrating past and current efforts, and what can be done in the future. Broad areas in which efforts can be promoted to improve the health of people with disabilities include improved access to health care and human services, increased use of data for decision-making, strengthening health and human services workforce capacity, renewed efforts to include people with disabilities in public health programs, and increased preparation for emergencies.

Specifically, compared to adults without a disability, the data showed that adults with a disability were more likely to be affected by:

- Certain social factors; adults with a disability were **more likely** to be
 - Unemployed
 - A victim of a violent crime
- Health and health risk behaviors; adults with a disability were **more likely** to
 - Have cardiovascular (heart) disease

- Be obese
- Be a current smoker
- Engage in no leisure-time physical activity
- Lack of health care access; adults with a disability were **less likely** to
 - Have a current mammogram
 - Be receiving needed medical care (because of the cost of care)

Factors Affecting the Health of People with Disabilities and without Disabilities



All estimates are for adults 18 and over, except for “victim of violent crime” which is for respondents 12 and over.

(1) Armour BS, Thierry JM, Wolfe LA. State-level differences in breast and cervical cancer screening by disability status: United States, 2008. *Womens Health Issues*. 2009;19:406-414.

(2) Rand MR, Harrell E. National crime victimization survey: crime against people with disabilities, 2007. *Bur Justice Stat Spec Rep*. 2009: NCJ 227814.

Implications/Recommendations:

1. **Improve access to health care and human services.** For example, use of accessible equipment in medical practice (such as wheelchair accessible scales) and compliance with the Americans with Disabilities Act (ADA) and the Affordable Care Act (ACA), which provide accessibility guidelines, could improve access.
2. **Improve data collection, and use it to advance public health standards.** For example, routine use of disability status in analyses, to provide information about relationship of disability status with health and health behaviors (such as smoking, physical activity, use of preventive care), could help provide health systems, as well as medical and public health professionals, with the needed information on where to focus to improve the health of people with disabilities across the lifespan.
3. **Strengthen the workforce.** For example, increased training of healthcare providers could support
 - Earlier identification and intervention for children with disabilities;
 - Improved services for youth with disabilities transitioning into the adult care system; and
 - Improved health care and health promotion for all people with disabilities.
4. **Include people with disabilities in public health programs and practices.** For example, organizations and systems would benefit from instituting specific policies and practices for including people with disabilities into mainstream programs and research.
 - Often, the changes programs make to include people with disabilities will improve the ability for ALL people to participate.
 - Plan for inclusion—facilities should be wheel-chair accessible, and information should be accessible by people who have trouble with vision, hearing, or understanding complex information.
5. **Prepare for emergencies with people with disabilities in mind.** For example, considering people with all types of disabilities in all preparedness planning activities could help meet their differing needs during emergencies (such needs might include assistive equipment and animals; medications; and accessible shelter facilities).

Centers for Disease Control and Prevention (CDC) Work on Disability and Health Disparities

CDC monitors the health of people with and without disabilities, and supports the inclusion of people with disabilities in public health programs that prevent disease and promote healthy behaviors. CDC also works to eliminate barriers to health care and improve access to routine preventive services.

CDC supports [18 state-based disability and health programs](#) and [four National Public Health Practice and Resource Centers](#), which promote healthy lifestyles and work to improve quality of life for people with disabilities. The primary goals of the state programs are to:

- Increase health promotion opportunities for people with disabilities.
- Improve access to health care services for people with disabilities.
- Improve [emergency preparedness for people with disabilities](#).

CDC also maintains the [Disability and Health Data System \(DHDS\)](#), an online interactive tool that provides instant access to state-level, disability-specific health data. Users can customize the disability and health data they view, making it easy to identify health differences between adults with and without disabilities.

More Information

To learn more about disability disparities and CDC's work in this area, please visit: <https://www.cdc.gov/ncbddd/disabilityandhealth/>

Additional Resources

- [CDC Vital Signs – Adults with Disabilities](#)
- [Disability and Health Data System](#)
- [Disability and Physical Activity: Resources for Doctors and other Health Professionals](#)
- [Grand Rounds archive: Where in health is disability? Public health practices to include people with disabilities](#)

- [CDC Feature: 10 Things to Know about Physical Activity among Adults with Disabilities](#)
- [Disability and Health website](#)
- [Disability and Health Programs](#)
- [Disability and Health Data System \(DHDS\)](#)



Exploring Health Disparities Among People with Intellectual and Developmental Disabilities

What Are the Issues and Do Race
and Ethnicity Play a Role?



Valerie J. Bradley,
Human Services Research Institute

NASDDDS Annual Meeting
November 13, 2014



Agenda



- Research questions
- What are health disparities?
- Health/healthcare disparities and people with ID/DD
- What do NCI data show?

Research Questions

- Do people with intellectual and developmental disabilities experience health disparities overall?
- Do NCI data demonstrate differences in utilization and access to preventive healthcare by race/ethnicity?
- Do NCI data demonstrate differences by race/ethnicity in other outcomes, such as employment, choice, community inclusion, and rights/respect?



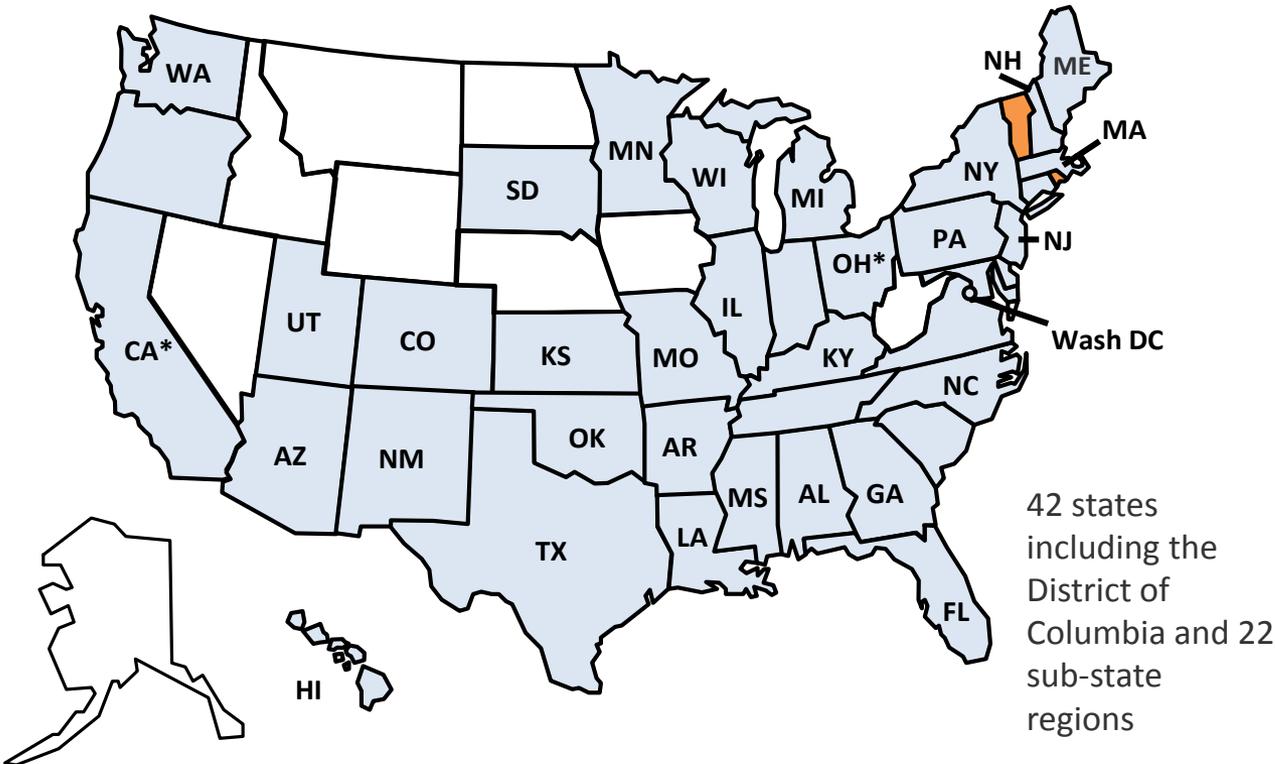
National Core Indicators (NCI)?



- NASDDDS – HSRI Collaboration
- Multi-state collaboration of state DD agencies
- Measures performance of public systems for people with intellectual and developmental disabilities
- Assesses performance in several areas, including: employment, community inclusion, choice, rights, and health and safety
- Launched in 1997 in 13 participating states – now in 42 states (including DC) and 22 sub-state areas
- Now expanded to elderly and people with disabilities through the NCI-AD



NCI State Participation 2014-15



■ State contract awarded in 2014-15 through AIDD funding
CA*- Includes 21 Regional Centers
OH*- Also includes the Mid-East Ohio Regional Council

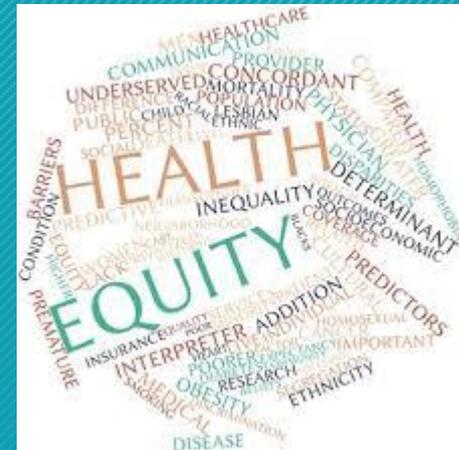


How Does NCI Collect Data?

- Adult Consumer Survey
 - ✓ In-person conversation with a sample of adults receiving services to gather information about their experiences
 - ✓ Keyed to important person-centered outcomes that measure system-level indicators related to: employment, choice, relationships, case management, inclusion, health, etc.
- Adult Family, Child Family, and Family/Guardian Surveys: mail surveys – separate sample from Adult Consumer Survey
- Other NCI state level data: Mortality, Staff Stability



What Are Health Disparities?



Health Disparity Populations

The National Institute on Minority Health and Health Disparities (NIMHD) defines the population as those with:

A significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality, or survival rates in the population as compared to the health status of the general population.



Health Disparity Populations

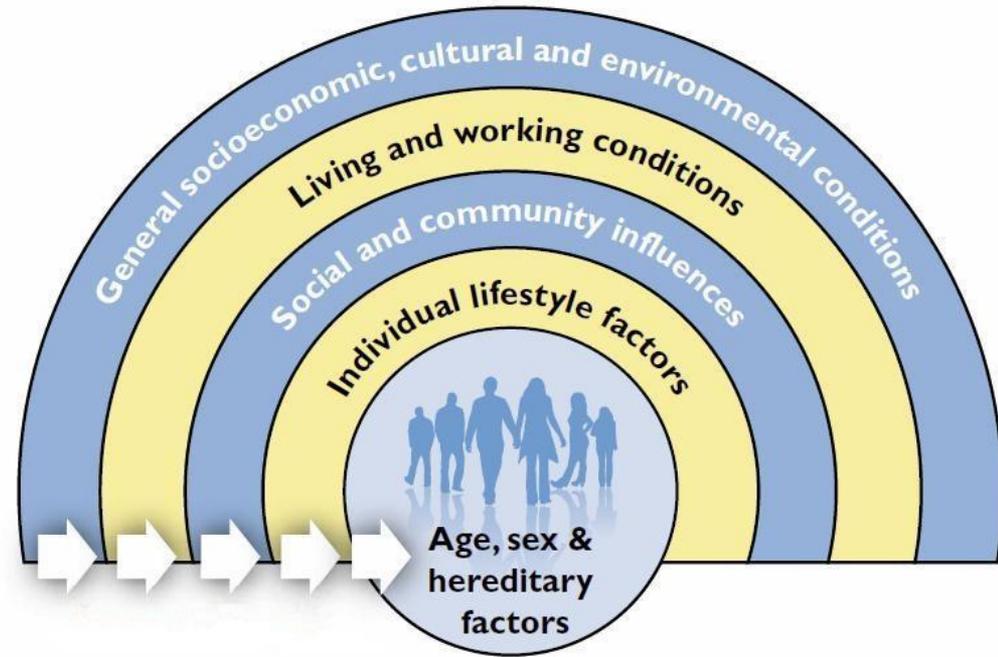
Current NIMHD health disparity target groups include:

- Blacks/African Americans
- Hispanics/Latinos
- American Indians/Alaska Natives
- Asian Americans
- Native Hawaiians and other Pacific Islanders
- Socioeconomically disadvantaged populations and rural populations
- **Disability advocates pressing for inclusion in the definition**



Health Determinants

- Why are some people healthy/unhealthy?
- Differences in health/healthcare utilization exist because of **unequal distributions of social, environmental, economic conditions within society**
- NCI captures demographics, employment, communication, choice., etc.



Health Determinants Model

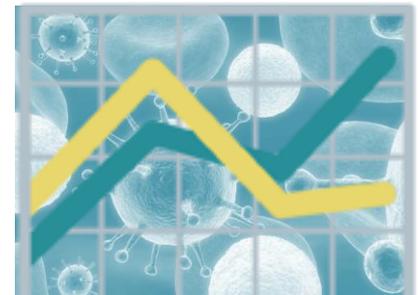
http://www.health-inequalities.eu/HEALTHY/EN/about_hi/health_inequalities/



**Do Individuals with ID/DD
Experience
Health/Healthcare
Disparities?**

ID/DD Population as Potential Health Disparity Population?

- American Academy of Developmental Medicine and Dentistry (AADMD), AMA, and ADA:
 - Advocating to have ID/DD population designated as “medically underserved” by Health Resources and Services Administration—would lead to increase in resources to address disparities
- People with ID/DD shown to be “socioeconomically disadvantaged*”
- People with ID/DD experience:
 - Higher rates of certain diseases/conditions
 - More deaths and morbidity from those diseases when compared with the general population



*Rehabilitation Research and Training Center on Disability Statistics and Demographics (StatsRRTC), 2004 Disability Status Reports 2004; Ithaca (NY): Cornell University



What Are the Top 5 Causes of Death in the General Population?

Rank	Cause
1	Heart Disease 24.5%
2	Cancer 23.3%
3	Emphysema, Asthma, Bronchitis 5.68%
4	Stroke 5.3%
5	Unintentional Injury 5.02%

<http://www.cdc.gov/nchs/fastats/leading-causes-of-death.htm>



What Do People with ID/DD Die of?

Comparison of the Top 5 Leading Causes of Death as Reported by Four State ID/DD Agencies

Rank	MA DDS CY2010 (Adults)	MA DDS CY2011 (Adults)	CT DDS45 FY2011 (all ages)	OH DDD47 2010 (Adults)	LA OCDD FY2011 (all ages)
Method	Underlying		Primary	Unknown	Unknown
1	Heart Disease 18.0%	Heart Disease 17.5%	Heart Disease 27.4%	Heart Disease 18.9%	Heart Disease 18.4%
2	Cancer 13.8%	Cancer 12.7%	Cancer 13.5%	Cancer 11.3%	Septicemia 17.3%
3	Alzheimer's Disease 12.8%	Alzheimer's Disease 10.9%	Aspiration Pneumonia 12%	Influenza & Pneumonia 9.0%	Congenital Condition 16.3%
4	Aspiration Pneumonia 12.3%	Aspiration Pneumonia 8.0%	Respiratory Disease4 11.1%	Congenital Diseases 8.3%	Pneumonia 10.2%
5	Septicemia 8.6%	Septicemia 7.7%	Pneumonia 8.2%	Aspiration Pneumonia 7.1%	Malignant Neoplasm (Cancer) 7.1%

At What Ages Do People with ID/DD Die?

Average Age at Death by Gender, 2011

Gender	Average Age at Death MA DDS	Average Age of Death US General Population
Female	62.5	81.1
Male	59.9	76.3

What Does the CDC Say About the Health Status of People with ID/DD?

Adults with intellectual disabilities experience poorer health outcomes than people without ID. These disparities mean that people with ID are more likely to:

- Live with complex health conditions.
- Have limited access to quality healthcare and health promotion programs.
- Miss cancer screenings.
- Have poorly managed chronic conditions, such as epilepsy.
- Be obese.
- Have undetected poor vision.
- Have mental health problems and use psychotropic medications.

<http://www.cdc.gov/ncbddd/developmentaldisabilities/index.html>



ID/DD Healthcare Disparities in Preventive Care Use

Women with ID/DD are less likely than women without ID/DD to:

- Have had cervical and breast cancer screenings
- Have ever visited a gynecologist

Individuals with ID/DD are less likely than individuals without ID/DD to:

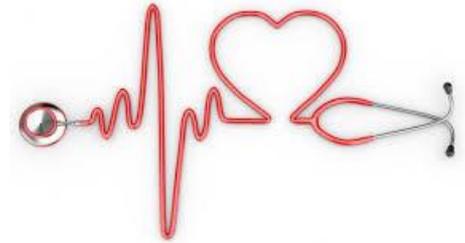
- Visit dentist regularly
- Get eye and hearing tests
- Receive timely vaccines





**Do Ethnic and Racial
Disparities Exist Regarding
Utilization of Preventive
Care?**

What Is Preventive Care?



- Prevents people from getting sick by detecting diseases/conditions before they become serious
- Beneficial for both financial purposes and to achieve a high quality of life
- Enhanced attention to preventive care:
 - **Patient Protection and Affordable Care Act (ACA)**
 - Requires that many health insurance companies cover the full cost to the consumer of many types of regular preventive care services (Healthcare.gov).

Racial/Ethnic Healthcare Disparities in Use of Preventive Care

General Public:

African American and Hispanic individuals

- Visit their personal physician and have dentist visits less frequently than whites
- Are less likely than whites to receive services such as
 - Flu and/or pneumonia vaccines
 - Colorectal cancer screenings
 - Pap tests
 - Mammograms





What Do NCI Adult Consumer Data Tell Us About Racial and Ethnic Disparities in Utilization of Preventive Care?

Data Source: Adult Consumer Survey

- Standardized, face-to-face interview with a sample of individuals receiving services
 - Background Information - includes health information
 - Section I (no proxies allowed)
 - Section II (proxies allowed)
- No pre-screening procedures
- Conducted with adults only (18 and over) receiving at least one service in addition to case management
- Section I and Section II together take 50 minutes (on average)



General Findings



- Individuals living in structured settings (i.e., specialized institutions, group homes) are more likely to have access to preventive screenings and vaccinations—regardless of their race or ethnicity.
- Individuals living with their families and those living independently are less likely to receive preventive care.

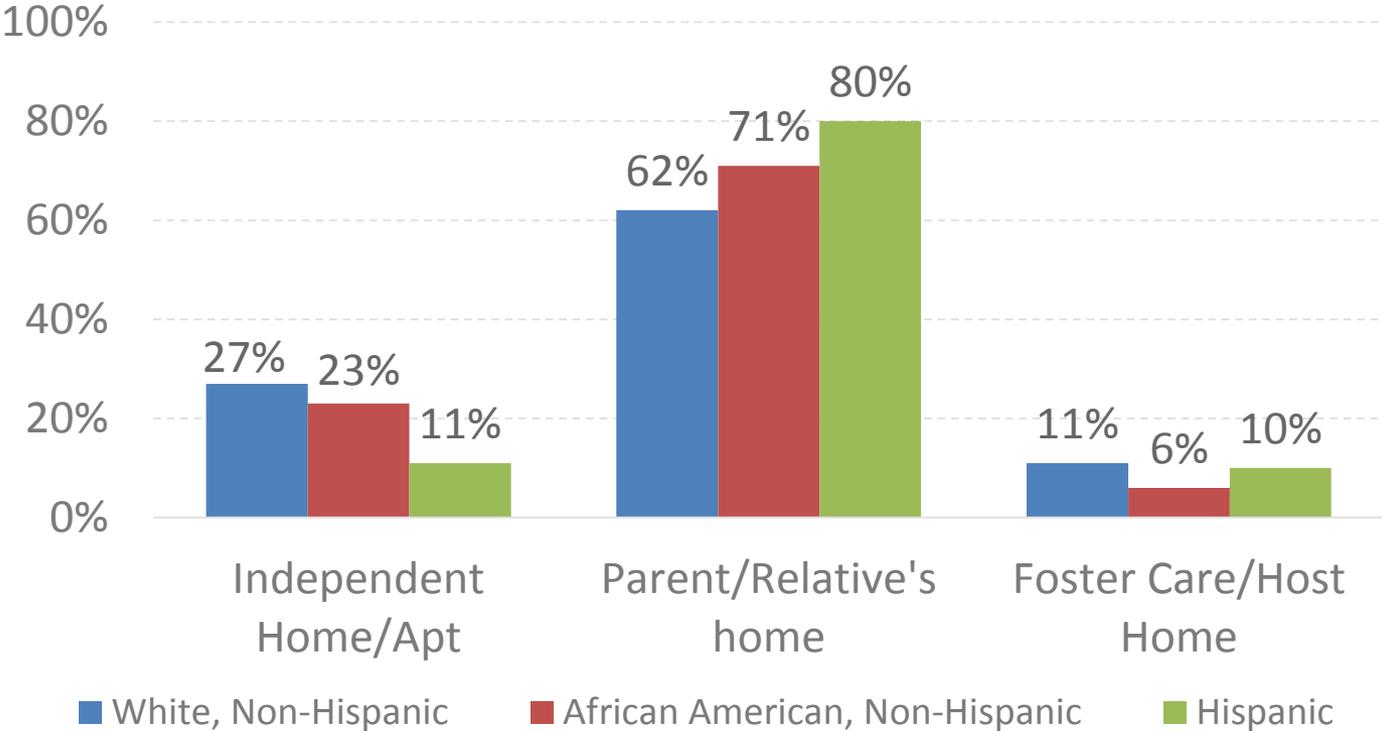
Residence Type

- To determine whether race or ethnicity played a role in access to preventive care, we only included individuals living in:
 - Independent home/apartment
 - Parent/relative's home
 - Foster care/host home
- N=7,632 from 25 states
- Race/ethnicity collapsed into 3 groups African American (non Hispanic), Hispanic (including black Hispanic), White (non-Hispanic)

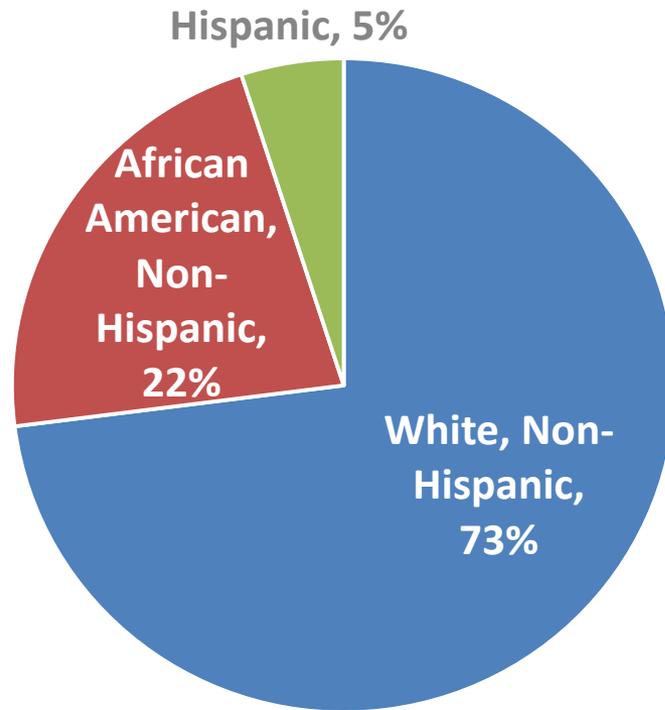


Demographic Differences

Final Sample Residence Type (p<=.001)



Race/Ethnicity of Individuals Living at Home, Independently or in a Foster Home/Host Home



Preventive Care Utilization Disparities

White respondents, African American respondents, and Hispanic respondents have significantly different rates of:



- Having had a physical exam in the past year ($p < .001$)
- Having gone to the dentist in the past year ($p < .001$)
- Having had a routine vision screening/eye exam in the past year ($p < .001$)
- Having had a flu vaccine in the past year ($p < .001$)
- Having ever had a pneumonia vaccine ($p < .001$)

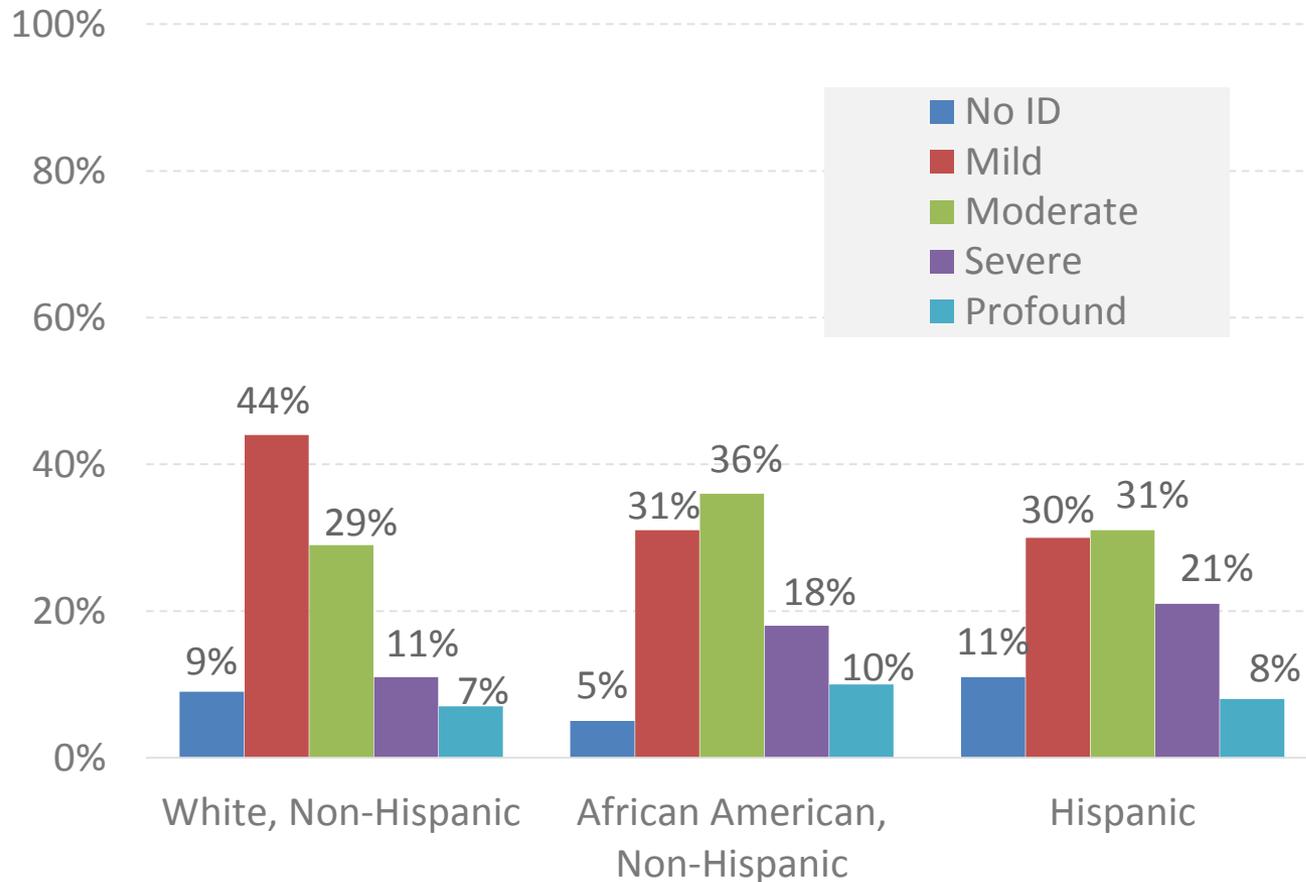
Important to Control for Other Factors

- Individuals of different races and ethnicities also differ in other demographic characteristics such as:
 - State of residence
 - Age
 - Individual's primary language
 - Individual's primary means of expression
 - Level of intellectual disability
 - Mobility
 - Other diagnoses (in addition to ID/DD)
 - Residence type
- These differences may affect their rates of preventive care use.
- Some examples of demographic differences are seen in the next few slides...



Level of ID by Race/Ethnicity

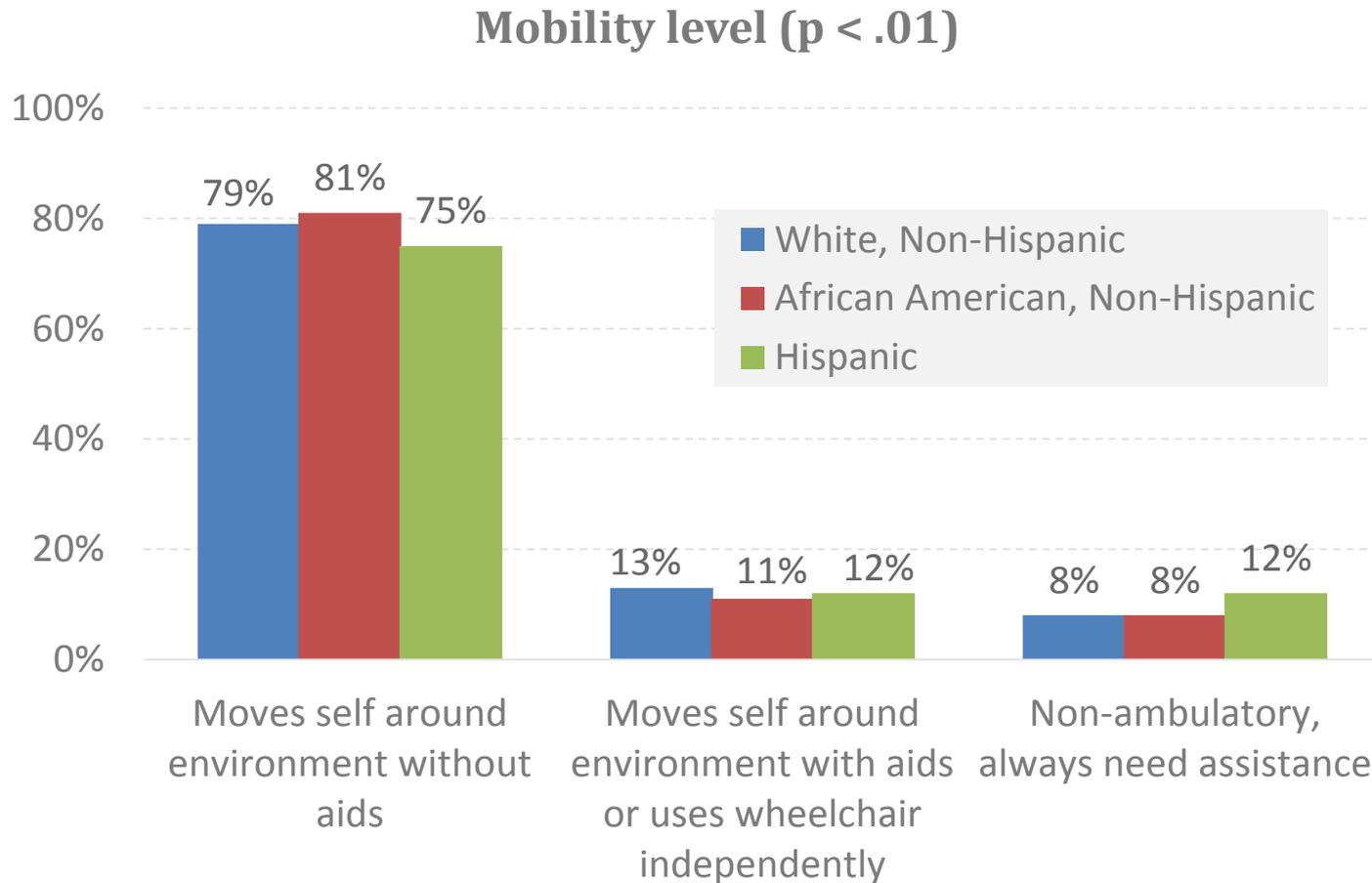
Level of Intellectual Disability (p<.001)



- White respondents more likely to be diagnosed with mild ID
- African American and Hispanic respondents more likely than White respondents to be diagnosed with moderate, severe, or profound ID

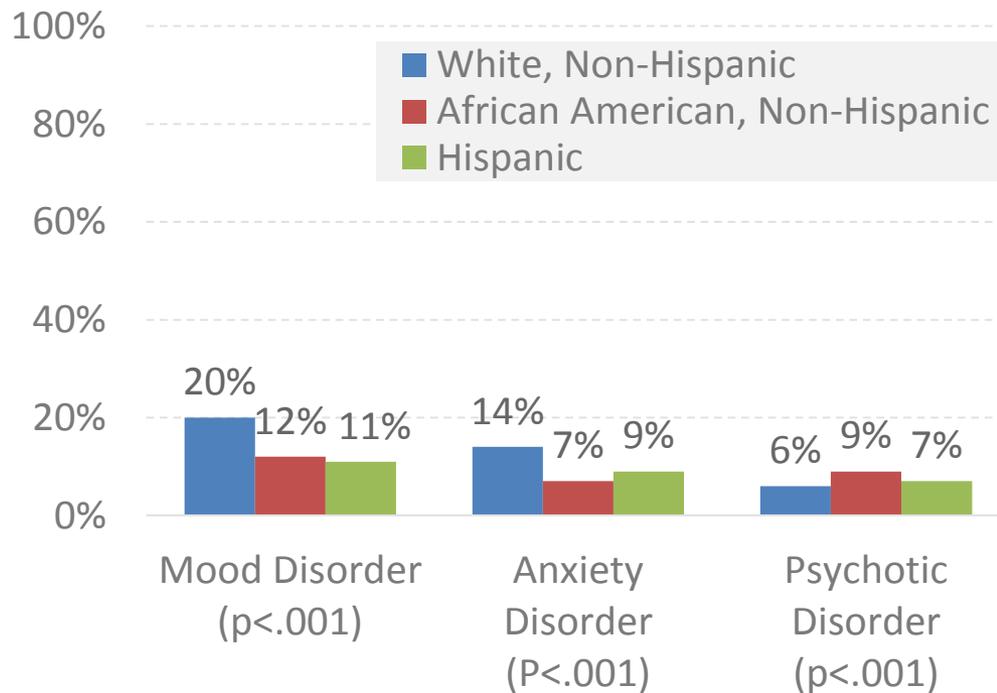


Mobility Level by Race and Ethnicity



Other Diagnoses by Race/Ethnicity

Mental Illness/Psychiatric Diagnosis



- White respondents are more likely to be diagnosed with mood disorder and/or anxiety disorder
- African American and Hispanic respondents more likely to be diagnosed with psychotic disorder

After controlling for demographic factors...

For individuals not living in institutional or community-based settings, the following preventive care exams showed differences by race/ethnicity that were still statistically significant:



African American respondents and Hispanic respondents were less likely than White, Non-Hispanic respondents to have had a physical exam in the past year.



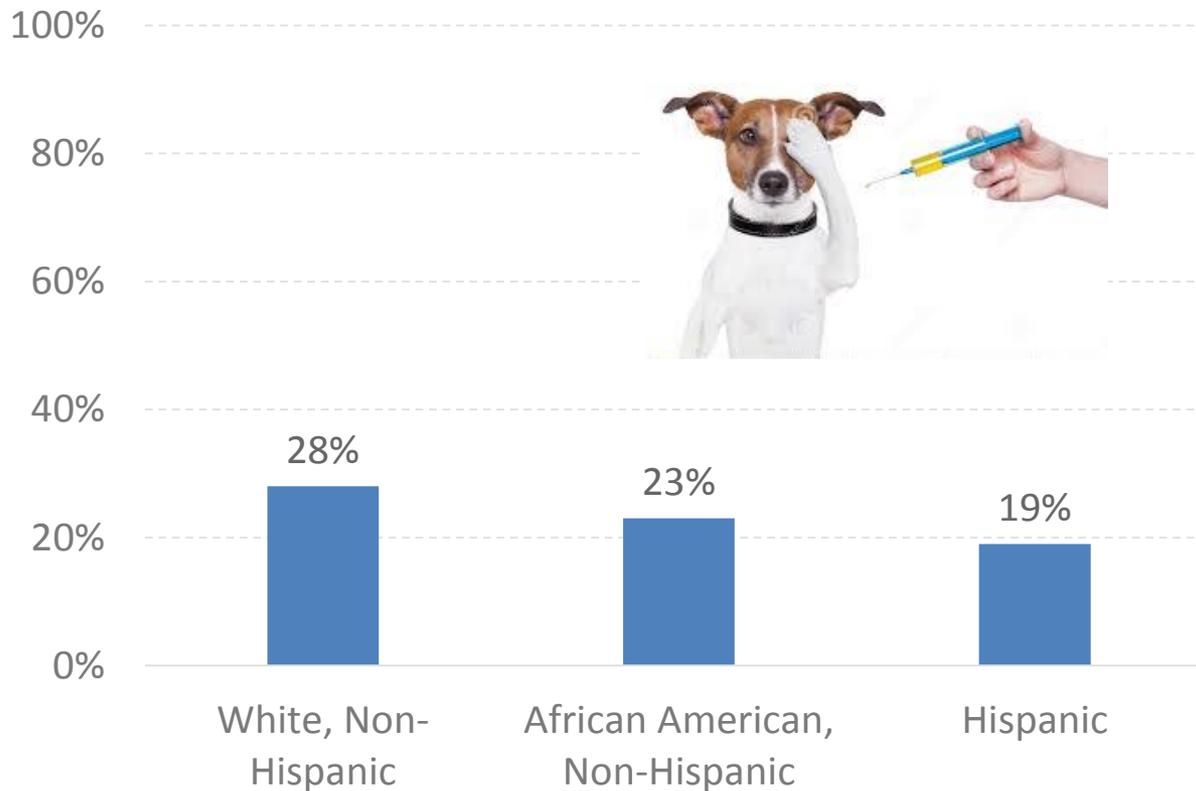
African Americans were less likely than Whites to have had a dentist visit in the past year.



African Americans were less likely than Whites to have had a flu vaccine in the past year.

Example:

Though Whites Are More Likely to Have Ever Gotten Pneumonia Vaccine ($p < .001$) – Bigger Predictor was Risk Factors Including Age (older), Down Syndrome, Poor Health, and Reduced Mobility

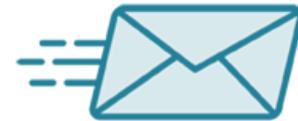




What Do NCI Adult Family Survey Data Tell Us About Racial and Ethnic Disparities in Access to Preventive Care?

Adult Family Survey 2012-13

- Mail-in surveys
- Adult Family Survey: respondent is a family member of an individual with ID/DD over age 18 who lives in the family home
- 2012-13: N=5,010
- 13 states



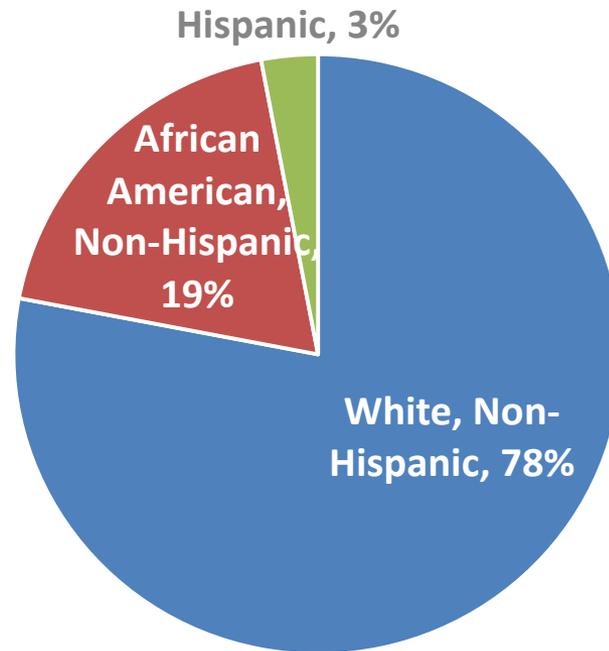
Administration of Adult Family Survey

- Mail-in
 - Selection bias!
- Sent to families with an adult family member living at home
- The Adult Family Survey (AFS) asks about *access* to health services as opposed to *utilization*. For example:
 - “Do you have access to health services for your family member.”
- Also asks about dental services, medications, and mental health services.



Demographic Breakdown

Adult Family Survey 2012-13 (N=4,760*)



*Only those cases for which a racial/ethnic identity was provided were included in this analysis.



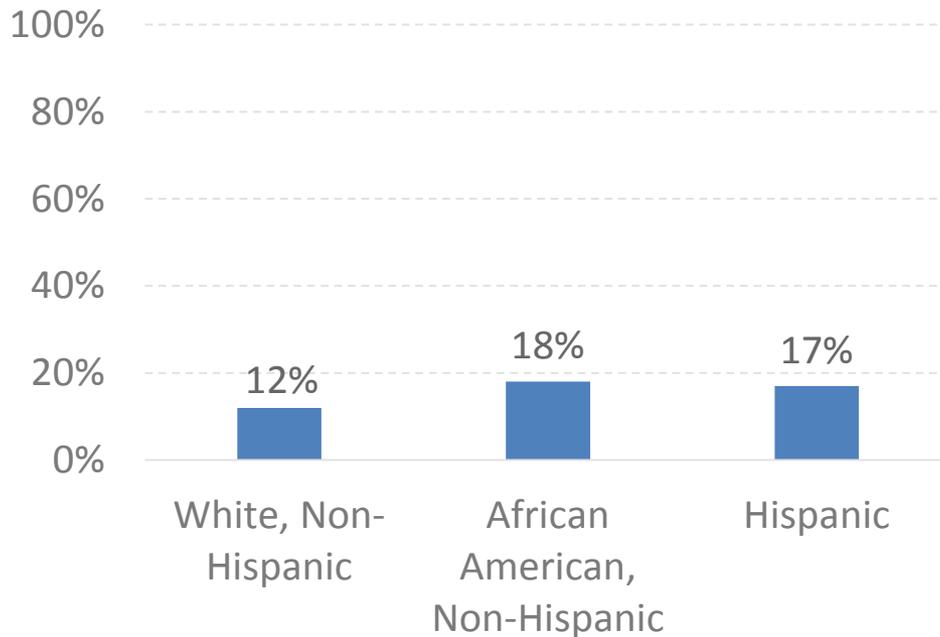
Though Data Showed Some Differences in Access (e.g., dental, doctors visits) Needed to Control For:

- State of residence
- Family member's age
- Whether there is more than one person with a disability in the household
- Family member's primary language
- Family member's primary means of expression
- Family member's other diagnoses (in addition to ID/DD)
- Family member's highest level of education
- Frequency at which family member requires medical care
- Whether family member needs behavior support
- Level of support family member needs for activities of daily living
- Respondent's highest education level
- Household income



For example...

More than One Person With ID/DD Lives in Household (p<=.001)



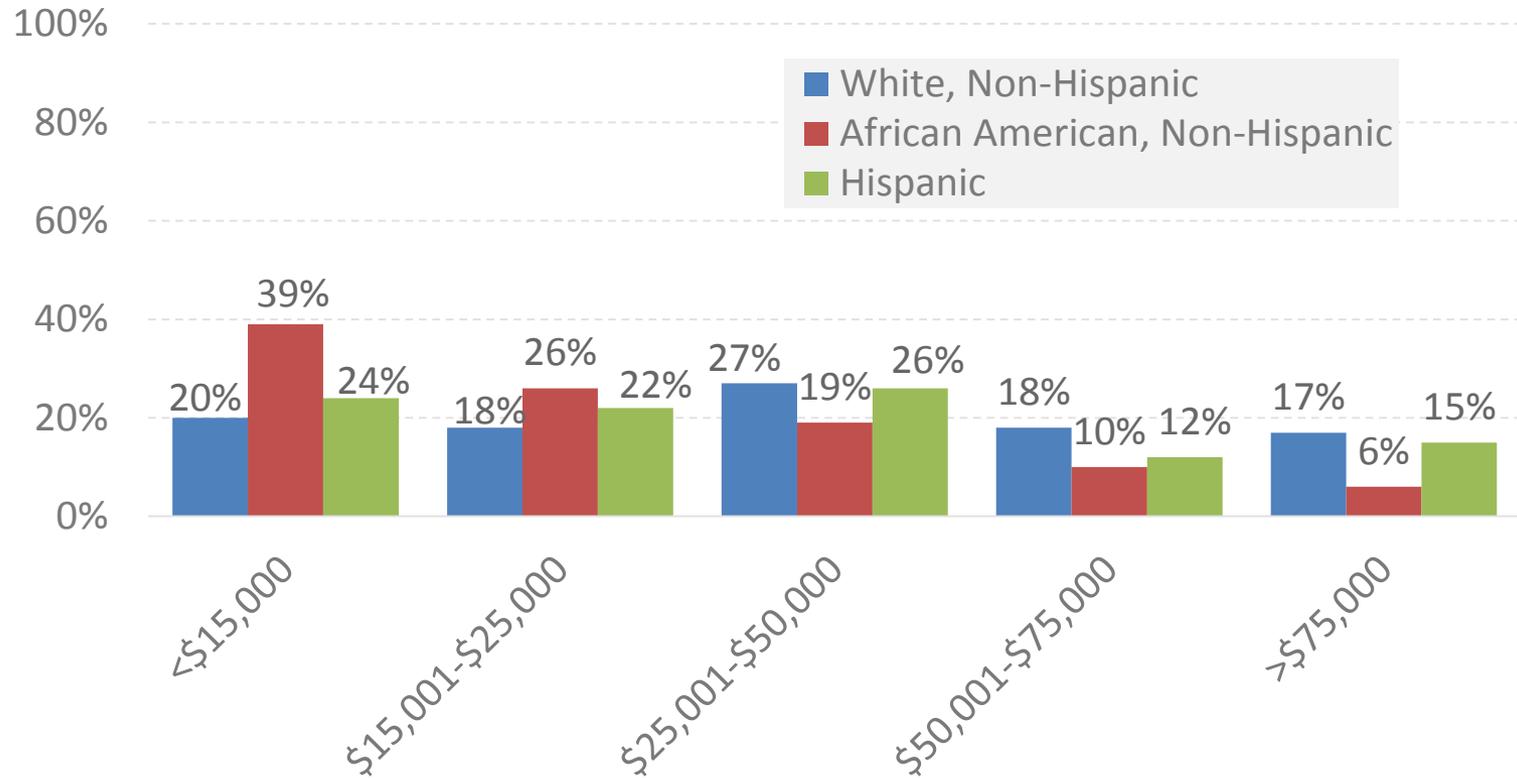
Hispanic respondents significantly more likely to need moderate or complete help with daily activities (such as bathing, dressing, eating) than White, Non-Hispanic and African American, Non-Hispanic respondents.



For example.....



Household Income in Past Year (p<=.001)



Findings

Interestingly...

- Household income is a significant predictor of access to dental care.

When we control for these demographic differences

- Race/Ethnicity is no longer a significant predictor of access to any of the preventive care specified in the AFS.



Do NCI Data Demonstrate Differences by Race/Ethnicity in Other Valued Outcomes?

Using full NCI ACS dataset: N=13,157

Other Outcome Disparities



There are significant differences in rates of paid community employment among the racial and ethnic categories.

In addition, among those who don't have a paid community job, African Americans more likely to want a paid community job.

White respondents were significantly more likely to have had at least some input in:

Choosing home, schedule, what to do in free time, and/or choosing day activity

Other Outcome Disparities (cont.)

Hispanic respondents are more likely to report that:



- Their email/mail is read without their permission
- There are rules against being alone with friends/visitors
- There are rules/restrictions on use of phone/internet

Summary

- While people with ID/DD do experience health disparities and are disproportionately affected by disease, and untimely death, they are not a federally designated group.
- People with ID/DD are more likely to die of preventable causes and to die at an earlier age.



Summary (cont.)

While a variety of factors may explain disparate access to preventive health services,



African American respondents and Hispanic respondents were less likely than White respondents to have had a physical exam in the past year



African Americans were less likely than Whites to have had a dentist visit in the past year



African Americans were less likely than Whites to have had a flu vaccine in the past year

Summary (cont.)

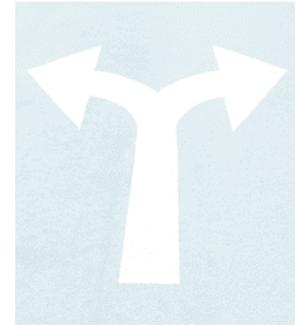


- Family income is a bigger predictor than race and ethnicity of access to preventive health services.
- NCI data show that African Americans and Hispanic respondents to the Adult Consumer Survey are less likely to achieve outcomes such as employment and choice and to have their rights respected.



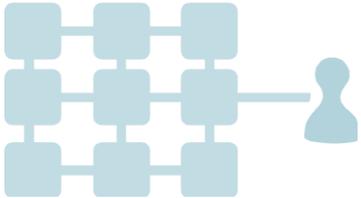
What To Do Now?

- Advocate that HRSA include individuals with ID/DD as a medically underserved population.
 - Allocate more resources to research into disparities
- As more people with ID/DD live in their own homes, with their families and in foster/host homes, public managers and MCOs will need to find other means to ensure that individuals with ID/DD utilize preventive services – especially in light of their health challenges
 - Track data
 - Targeted outreach campaigns to different populations



What To Do Now? (cont.)

- Conduct continued research into racial and ethnic disparities in preventive and general healthcare
 - Help tease out root causes/social determinants of disparities and what can be done to mitigate them
- Support more systematic examination of mortality data for individuals with ID/DD
- Track the implementation of the ACA including broader coverage, better training, more accessible facilities
- Explore reasons for differential results regarding employment, choice, rights



Selection of References:

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For more, please contact dhiersteiner@hsri.org



Contacts

HSRI

Val Bradley: vbradley@hsri.org

NASDDDS

Mary Lee Fay: MLFay@nasddds.org

NCI website

www.nationalcoreindicators.org



NASDDDS





VOICES of SSAN

September 2018 Volume 14

California Wildfires Devastating & Possible Resources By Robert Levy SSAN Rep from the UCEDD UCD MIND Institute



This year the state had major wildfires. As of October 3rd, about 1.5 million acres have burned across the state. The fires began in the middle of August. In the North Coast office area almost 459,000 acres has burned. In the Sequoia office area, a little bit over 100,000 acres has burned. In the San Bernardino office area almost 23,000 acres has burned. That fire was intentionally set by a human who was arrested for starting that fire. In the North

State office area the wildfire has burned little over 211,000 acres. The wildfire in Shasta County has burned over 6,000 acres. This is a bad fire season for another year. It is like it is now the norm for year round fire season.

Here are some links to resources:

California Conservation Corps
<https://ccc.ca.gov/>

California Department of Fish of Game and Wildlife
<https://www.wildlife.ca.gov/>

California Department of Forestry & Fire protection
<http://www.ca.gov/Agencies/Forestry-Fire-Protection-California-Department-of> .

(Continued on page 2)

In this edition of the
Voices of SSAN

A Day on the Job

**Self-Advocacy &
Health**



Check out the
Statewide Self
Advocacy Network
(SSAN) webpage at
www.sccd.ca.gov/selfadvocacy



SSAN Newsletter
Editor -Robert Levy

**Contributors to
this edition:**
Chen Curtiss
Robert Levy
Paul Mansell
Teresa Moshier
Nicole Patterson
Regina Woodliff



(Continued from Page 1)

The California Park
(U.S National Parks.)
[https://www.nps.gov/
state/ca/index.htm](https://www.nps.gov/state/ca/index.htm).

American Red Cross
<https://www.redcross.org>.



**American
Red Cross**

The firefighters are hard workers and they risk their lives to put these fires out. This includes the Department of Corrections, which is also helping out the firefighters on the front lines. There are over 20,000 firefighters and prison inmates that are working hard to get these fire put out. There are at least over 1,000 homes other businesses has been effected.
.....

Dr. Oz By: Chen Curtiss



Do you like watching TV?

Do you like being healthy?

Then you will love watching Dr. Oz. He is a doctor who has a tv show on the NBC network. Dr. Oz shares with the public information about health that is good to learn.

Also he has a good sense of style, always well dressed with a suit and a watch. He has a good personality too - he makes people happy when he tells the truth about health topics. For example,

he suggested drinking raw apple cider vinegar and water dilution daily to help with food digestion. It's important not to follow medical advice without checking with your personal doctor beforehand. So, try to remember to ask your doctor about it first before trying some of Dr. Oz's suggestions.

He is on TV daily, Monday through Friday. He also has a website (<https://www.doctoroz.com/>) where you can find health tips. They have food recipes with videos to show you how to make them. You may also consider signing up for his newsletter while on the website. There is a phone app too.

Pictured: Chen Curtiss





**A Day on the Job
By Regina Woodliff**

My job is working with people who have developmental disabilities. Some of the people need more help than others. There are about 40-42 individuals who attend the day program I work at.

To get to my job, I have to take an early bus to Concord. When I get to work, I have to sign in. I also check the daily log sheet to see what I am assigned to do that day.

Sometimes we start with exercise, or go out on outings, like going to a Farmer’s Market, go bowling, go to the movies, go to

San Francisco and go to Art and Wellness. Art and Wellness is a program where people can do arts and crafts.

My job is to help people with what they need while we are out, like help to get onto the bus, help with their money transactions or anything else a person may need.



When we return to the day program, I help with any personal care needs or eating assistance.

I talk with the people at the day program to see what things they would like to do each month. They chose what they want to do

like eating lunch at a park, playing bingo or listening to music at Todos Santos Plaza. We mark the activities on the calendar.

I get off work about 3:30pm. I catch the bus to the Bart Station and then another bus to get home. I get home around 5:15 pm.

I have had this job for years. I started out as a participant at the day program myself and I became an aide in May 2007. I am classified as an aide now, but my goal is to be an attendant and then an instructor.

I enjoy my job and every morning I look forward to going to work because the people mean so much to me. I am very grateful to people who helped me. “I thank God for this job!”



Region 2 People First 2018 Conference

by Teresa Moshier
North State

We titled our Region 2 People First 2018 Conference as, “People First Comes Together, Stays Together Forever.” Our North State Region recently celebrated the Region 2 People First Conference on May 18-20, 2018 in Anderson, California at the Gaia Hotel. We had break-out sessions including: “Feeling Safe, Being Safe,” “Healthy Living,” “History of the Developmental Centers in California and How they are Closing” and more topics! We also had keynote speakers including Paradise People First Chapter

Officers, that facilitated a question and answer session related to the People First Organization. A member of the Chico People First Chapter and former President of People First of California shared her story on how she got involved in People First.

All 6 Region 2 People First Chapters helped plan the conference. As the first female President in the history of Paradise People First Chapter, it was really fun to organize the dance and our chapter decided on a “Prom” theme. Everyone came dressed in their favorite “Prom” outfits and it was a great dance!

Our conference was a success and about 150 self-advocates, helpers

and staff attended. The Chapters are planning to review the conference surveys to learn what went well and what to improve on for the next conference in 2020!



Self-Advocacy and Health

By Paul Mansell

Self-Advocacy is all about speaking up for ourselves, making choices, and being responsible for decisions and actions. Our health is an important part of Self-Advocacy. Health is more than being sick or injured. Health includes diet, exercise, sleep, and much, much more. **(Continued on Page 5)**



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It includes how our body and mind are working. When they are working well and in harmony, we feel more alive, capable, and positive. It is important to get a check in from a doctor or other health care professional for guidance to have the best possible health. Two people who have the same height, weight, and age may have dramatically different health care needs. Maintaining your health can be quite simple but it does require consistency and follow through.



**SSAN member
Highlights
by Robert Levy SSAN
Representative of the
UCD MIND Institute
UC/CEDD**



Hello my name is Robert Levy and I represent the UCD MIND Institute UC /CEDD here in Sacramento. I have been involved with the Statewide Self Advocacy Network since the group began on April 11, 2012. Since I have been part of the group I have been helping out by getting the new members learning what we do at SSAN. I have done a lot of different presentations

in our community. In 2015, I attended to leadership training in Seattle Washington and I stayed in the dorms in Seattle Pacific University. I have let people know about self-advocacy at Progressive Employment Concepts, the UC Davis MIND Institute staff members and other people out in the community. I have been doing a lot of Audio Video recording interviews on the UCD MIND Institute website. I was just featured on the Progressive Employment Concepts website under the Participants page.

I also have been chosen to part of the panel with the State Council for Developmental
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 Disabilities to talk about my part time jobs on Integrated Competitive Supported Employment at Target, UCD MIND Institute UC/CEDD and Progressive Employment Concepts.

Work can transform your life making it more exciting, fulfilling, and meaningful. Work doesn't come easily, but where there are challenges there are also rewards.

**Tailored Day Service Option
 Paid Internship
 By Paul Mansell**

Tailored Day Service option is for clients who don't fit into the traditional supported employment model. It includes employment,

volunteer, self-employment, and education options. This includes Vocational Assessments and Career Exploration (going to One-Stop Career Centers), resume development, job Development, interview preparation, job placement, volunteer placement with recognized non-profit entities, job coaching or volunteer supports (within maximum monthly hours), micro-business or self-employment, post-secondary education includes: adult Education, vocational certificates, GED, Community College (credit courses with educational plan) or non-credit courses, and four-year university degree. Leading an integrated and inclusive life

includes: mapping their community, becoming



a member of a group, club, or team (of non-disabled peers) sharing the same interests, enrollment in free or low-cost classes through local libraries (literacy classes) or park & recreation centers, membership in local fitness centers in order to maintain health and have regular exercise. Participants are fully engaged, as much as possible, in making decisions about their services. Participant choices, while highly valued, must result in specific measurable goals that fit the identified domain areas, and result in outcomes
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 that can be identified and measured. Paid Internship state law encourages competitive integrated employment (CIE) for individuals with intellectual and developmental disabilities. The goals of this program include the gaining experience and skills needed for future paid employment, typically in the same job field or industry. Internships can be traditional, or in the form of apprenticeships, including self-employment. The funds provided for the internship are used for wages (minimum wage or higher) as well as the related payroll costs. Each individual client is eligible for up to \$10,400.00 per year in an internship, and

could receive more than one internship. Any San Diego Regional Center client who is eligible for employment (18 and older) with eligibility to work, and expresses a desire to be employed (either part-time or full-time). Clients also need to be able to travel independently, or have some dependable transportation (ADA Paratransit, Uber/Lyft, family member, etc.) Regional Centers are now permitted to provide paid internships to transition-aged students 18-22 based on a need determined by both the Individual Education Plan (IEP) and Individual Program Plan (IPP) planning teams.

GOOD VIBRATIONS



By Paul Mansell

Fall is the time to breathe in and out and enjoy all the good things in your life. One way you can do it is take the StrengthFinder Survey Assessment. It is fun and doesn't take a whole lot of time. I took the survey and my top 5 themes were intellection, connectedness, input, strategic, and futuristic. My strengths may not be all that practical, but they do show I like to think. I have been told that I live in my head. I don't know about that,
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but I can't think of anything more exciting than to come across a new idea and sharing it with others.

At the June SSAN meeting, we talked about mental health disabilities and wellness. Some members identified they live with various issues of mental health disabilities. I report that I live with various forms of mental health issues and my goal is to achieve the maximum level of mental health possible for me in order to achieve wellness—mind, soul, and body balance.

Life can feel like a real grind sometimes and be exhausting. When faced with times like these, it is important to know what really excites you and energizes you. It may

be reading a good book, listening to good music, cooking a good meal, watching a good movie, or hanging out with family or friends. I have been told going out and buying a new pair of shoes can be very enjoyable. It is important to remember that life is to be enjoyed and savored like fine wine and cheese. Life is to be celebrated. It is more than to-do lists, duty or obligation. I find it tempting to think about all the problems in my life and to be very critical with myself and with others. When I find myself doing this, I challenge my criticalness with focusing on how much I have to be grateful and thankful for in my life. I have my job, my apartment, my bus pass, my iPhone, my

Mac, my TV, my health, family and friends, my education, my self-advocacy involvements, my books, and the Y. I confess that if I gave it more thought I could find a lot more to be thankful for in my life. With my education in political science, philosophy, and economics, I like to think about big thoughts. I am especially into fairness. My thoughts may not always be novel, but they are important to me and give my life meaning. For example, I feel strongly that goods, services, income and wealth, and opportunity should be allocated by talent and ability regardless of race and culture, gender or sexual orientation, language,
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 religion, or political affiliation. As far as disabilities, I feel a just, benevolent, and enlightened state provides supports and resources to empower individuals living with disabilities to reach their full potential. The state also has the obligation to ensure people have their basic needs met. People living with disabilities in turn have the challenge and opportunity to achieve their full potential. So this fall, let's claim and own all the good things in our life. It will make a big difference in our lives, in our friends and family, and the people we serve. The Beatle's song "Let it Be" comes to mind as does the saying "Stay calm and carry on".

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SELF-DETERMINATION PROGRAM (SDP) UPDATE



The Department is very pleased to have the application for federal funding, or Waiver, for the Self-Determination Program approved by the Centers for Medicare and Medicaid Services (CMS). While approval of the Waiver represents the key step towards the starting of the Self-Determination Program, the Department and the self-determination advisory workgroup must complete the following before the SDP can begin. The list below is not everything that needs

to be done, but includes the key parts and steps that are being worked on, also has the target dates for each one to be completed.

The Department will post updates on the progress.

- **Federal Funding Approval**
 Status: Completed. The application for federal funding, or Waiver, was approved by the Centers for Medicare and Medicaid Services on June 6, 2018.
- **Individual Budgets**
 - Target for completion: August 15, 2018
- **Financial Management Services (FMS)** -
 Target for completion: August 31, 2018.

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- **Independent Facilitators** – Target for completion: August 31, 2018.
- **Participant Selection** - Target for completion: October 1, 2018
It's important to note that only those individuals who have participated in an informational meeting and whose names have been received by the Department by September 17, 2018 at 5:00 PM will be considered for selection (by the Department)
- Of the first 2,500 participants in the SDP. Individuals whose names are received after September 17, 2018 will be considered

for subsequent selections of SDP participants. Subsequent participant selections will occur if some of the initial 2,500 participants choose not to enroll or they enroll, then decide not to continue in the SDP.

- Information for those who are interested on how they can be considered for participation in the SDP can be found at www.dds.ca.gov/SDP/sdpEnrollment.cfm.
- **Home and Community-Based "Settings" Requirements** - Target for completion: October 31, 2018.

- **Orientation Materials** - Target for completion: October 31, 2018.

Terms to remember in SDP:

Independent Facilitator – is a person who can help you make decisions about your individual budget as well as find and organize services and supports that are in your IPP. They can also help you lead, participate, or advocate for yourself in the person-centered planning process and help in creating your IPP.

Financial Management Service (FMS) – is a company or person who will help you with handling your money, paying your workers, and processing background
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 checks for your workers. The cost of the FMS comes out of your individual budget. The Financial Management Service manages the individual budget based on your plan.

If you want more information on SDP, please visit the Consumer Corner SDP page at <https://www.dds.ca.gov/ConsumerCorner/sdp.cfm> or if you have other questions about SDP, please email us at sdp@dds.ca.gov.

**The SCDD
 Employment Panel
 Presentation By
 Robert Levy UCD
 MIND Institute
 UC/CEDD SSAN Rep**

On 7/31/18 SCDD invited fellow SSAN Member Desiree

Boykin and myself to talk at their meeting at the Crowne Plaza Hotel in Sacramento. I talked about my part time jobs at Target, the UCD MIND Institute and Progressive Employment Concepts. I also talked about what I've learned about the job tasks that needed to be done on typical work day. Desiree also talked about her typical work day at the ARCA in South Central Los Angeles area. There were others who spoke on the Employment panel presentation. They all learned a lot from me and the others.



SSAN Members

- Vacant North Coast
- Teresa Moshier North State
- Lisa Cooley Sacramento
- Chen Curtiss North Bay
- Regina Woodliff Bay Area
- Robert Balderama North Valley Hills
- Vacant Central Coast
- Rebecca Donabed Sequoia
- Julie Gaona Los Angeles
- Sean Sullivan Orange County
- Daniel Fouste San Bernardino
- Paul Mansell San Diego Imperial
- Desiree Boykin ARCA



- Vacant CFILC
- Nicole Patterson
DDS
- Scott Barron
DRC
- Robert Levy
Mind Institute
- Kecia Weller
UCLA Tarjan
Center
- Wesley
Witherspoon
State Council on
Developmental
Disabilities and
USC Childrens'
Hospital

SAVE the DATES:

Check out the December issue for recaps on the **Supported Life Institute** which happened on October 4-5, 2018 in Sacramento

AND

Jobtoberfest

Job and Resource fair for People with DisABILITIES, Which happened on October 22, 2018
Balboa Park Club
2144 Pan American Rd
San Diego, CA 92101

Paul Mansell
Employment
San Diego People First
Quarterly Meeting
9:30-2:00, Nov 5th
4355 Ruffin Rd, Ste
100
San Diego, CA 92123

“Collaborating for Effective Services”
5th Annual Leading the Charge
Doubletree Hazard Center
7450 Hazard Center drive
San Diego, CA



As of Monday August 6, 2018, both Office location has just moved being the State Council for Developmental Disabilities headquarters and the Sacramento Regional office. The address is at 3831 North Freeway Blvd. Suite #125 Sacramento, CA 95834. Please contact Riana Hardin if you have any questions: riana.hardin@scdd.ca.gov and will be glad to answer all the questions too.

People First Overview

People First is a national self-advocacy organization and international, national, and statewide movement of people with developmental disabilities. People First means that we are People First and our disabilities are second. Bay Area People First is the regional group that supports the local chapters within the region. The five local chapters are Alameda, Contra Costa, San Francisco, San Mateo and Marin. Bay Area People First meets every three months, while the local chapters usually meet once a month. The meetings are run by elected officers of every chapter.

The purpose of People First is to assist members in building self-confidence by providing a safe place to say how they feel and what they think. It is believed that a person who is given opportunity, training, and support with a peer group can learn to be a strong self-advocate for themselves and others. In People First meetings, members are given the opportunity to learn, practice, and develop their skills in public speaking, decision making, and problem solving.

Goals

- To feel good about oneself
- To move toward greater independence
- To be able to communicate for oneself
- To learn to be assertive
- To have respect for oneself
- To be appreciated
- To seek out and identify with a community of friends
- To be able to receive services from people of one's choice
- To be a valued member of one's community
- To be productive
- To work for positive change
- To have an impact on others
- To secure enjoyment in daily activities
- To experience variety in daily routines
- To explore that which is unknown
- To have control over decisions and choice making in one's life
- To know one's rights and responsibilities
- To educate the public about capabilities and goals of people with developmental disabilities

Meet a few Bay Area People First Officers

Christina Lason – has been with People First for more than 30 years. She is the current President for Bay Area People First and President for the Northern Alameda Chapter.

Sara Desumala – has been with People First for more than 25 years. She lives in San Francisco and likes going to the meetings because it educates her about speaking for herself and others.

Jerry Grace – represents our area for People First of California. He is part of the planning committee that puts together the annual ‘Gathering’ for People First members throughout the state.

Statewide Self-Advocacy Network (SSAN)

The **Statewide Self-Advocacy Network (SSAN)** is a member-led self-advocacy group supported by the State Council on Developmental Disabilities. It promotes leadership development, inter-agency collaboration, and being representatives at the table of policy makers. It has 4 (four) focus groups; Self-Determination, Employment, Legislation and Newsletter/Communications.

Vision – to build a statewide peer advocacy network that links, advocates, communities, regions and statewide leadership

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

Invited Network Partners Include:

Department of Developmental Services, Disability Rights California, UCEDDs (UCLA, USC, UC DAVIS), People First of California, State Council on Developmental Disabilities, Association of Regional Center Agencies, and California Foundation for Independent Living Centers.

SSAN holds general meetings four times a year around the Sacramento area. Each SSAN meeting includes member reports on issues and concerns in their regions, legislative updates, training for members, and resources to distribute to member's communities.

Regina Woodliff – has been representing our region and the SCDD Bay Area Office on SSAN for the last six years, since its inception. She served as Vice Chairman for SSAN 2 years ago. SSAN has helped Regina expand her knowledge in advocating for herself and others.

"I have been a member of SSAN since 2012 and I have seen SSAN grow so very much in those five years! SSAN is a cross disability training network and my personal passion is reaching out to the youth in the community. I want SSAN to have youth members from different disability related groups!"