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Teleconference Location:

SCDD HQ OFFICE

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MEETING ID: 828 5305 3326

MEETING PASSWORD: 688239

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STATE COUNCIL ON DEVELOPMENTAL DISABILITIES SELF-ADVOCATES ADVISORY COMMITTEE MEETING

POSTED AT: www.scdd.ca.gov

DATE: March 18, 2024

TIME: 1:30 P.M. to 4:30 P.M.

COMMITTEE CHAIR:

Eric Ybarra

Item 1. CALL TO ORDER

Item 2. ESTABLISH QUORUM

Item 3. WELCOME AND INTRODUCTIONS

Item 4. PUBLIC COMMENTS

This item is for members of the public only to provide comments and/or present information to the Committee on matters not on the agenda. Each person will be afforded up to 3 minutes to speak.

Additionally, there will be up to 5 minutes allocated to hear from the public on each agenda item, with each person allotted up to 1 minute to comment.

Item 5. APPROVAL OF JANUARY 22, 2024 MINUTES



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Item 6. EMERGING ISSUES AND CONCERNS **Page 11**

- A. Updates/concerns from regional advisory committees
- B. Regional emerging issues or barriers to self-advocacy
- C. Recommendations for future meetings and projects

Item 7. STATEWIDE SELF-ADVOCACY NETWORK (SSAN) REPORT **Page 13**

Item 8. REVIEW OF COUNCIL BUSINESS **Page 15**

Presented by: SCDD Executive Director Aaron Carruthers

- A. SCDD agency updates
- B. Statewide updates
- C. Nation updates
- D. Cycle 47 Grant Process

ITEMS RELATED TO COUNCIL BUSINESS ARE INCLUDED IN THE COUNCIL PACKET

**Item 9. PERSON-CENTERED ADVOCACY VISION
EDUCATION (PAVE) PROJECT**

**Page 17
Plus Handouts**

Presented by: CA Community Living Network (CCLN) Representative

**Item 10. DEVELOPMENTAL DISABILITIES AWARENESS MONTH
DISCUSSION**

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Item 11. ADJOURNMENT

Next Meeting: May 20, 2024

Accessibility

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All times indicated and the order of business are approximate and subject to change.

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MARCH 18, 2024

AGENDA ITEM 5

ACTION ITEM

**SELF-ADVOCATES ADVISORY COMMITTEE (SAAC)
STATE COUNCIL ON DEVELOPMENTAL DISABILITIES**

Approval of JANUARY 22, 2024 Minutes

Action Recommended

Approve the January 22, 2024 SAAC Minutes

Attachments

- January 22, 2024 SAAC Minutes

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**SELF-ADVOCATES ADVISORY COMMITTEE (SAAC) MEETING
MINUTES
JANUARY 22, 2024**

Members Present

Nicole Adler (SA)
Julie Gaona (SA)
Julio Garnica (SA)
Sonia Jones (SA)
Nester Nieves (SA)
Kara Ponton (SA)
Alex Reyes (SA)
Rosanna Ryan (SA)
Wesley Witherspoon (SA)
Eric Ybarra (SA)

Others Attending

Rihana Ahmad
Renee Bauer
Michelle Cave
Brandi Halstead
Riana Hardin
Dena Hernandez
Patricia Herrera
Beth Hurn
Christy Lam-Julian
George Lewis
Charles Nguyen
Nicole Patterson

1. CALL TO ORDER

Committee Chair Eric Ybarra called the meeting to order at 1:30 P.M.

2. WELCOME AND INTRODUCTIONS

Committee members and others in attendance introduced themselves.

3. ESTABLISHMENT OF QUORUM

A quorum was established.

Legend:

SA = Self-Advocate

FA = Family Advocate

4. PUBLIC COMMENT

Christy Lam-Juilan, a mother of an 8-year-old who received a late-diagnosis of a disability, requested that the Council look into the gap between anti-bullying and anti-sexual harassment of people with I/DD.

5. APPROVAL OF NOVEMBER 27, 2023 MINUTES

Members reviewed the minutes from the November 27th, 2023 meeting. The minutes can be found starting on page 7 of the January 2024 SAAC packet.

ACTION 1

It was moved/seconded (Witherspoon [SA]/ Ponton [SA]) and carried to approve the November 27th minutes as presented. All members present voted in favor of the motion.

6. MEMBER UPDATES

Members had an opportunity to share their updates and concerns about issues in their local area. Members brought up the ongoing need to promote inclusion of people with disabilities in all aspects of community living. Members would like to see greater awareness of the work that SCDD does and make sure that Regional Advisory Committee (RAC) meetings and SCDD committee meetings have better attendance. Members talked about the need to do outreach to media outlets about SCDD's work. Self-Determination, employment, and the accessibility of health care services were also brought up as ongoing opportunities for improvement.

7. STATEWIDE SELF-ADVOCACY NETWORK (SSAN) REPORT

SCDD SSAN Representative, Alex Reyes, provided a verbal report of the December SSAN Meeting.

Legend:

SA = Self-Advocate

FA = Family Advocate

8. REVIEW OF COUNCIL BUSINESS

SCDD Manager, Rihana Ahmad provided members with an update on the status of the agency and an overview of the January Council meeting agenda. Members of the Committee expressed an interest in hearing about the impact the Governor’s proposed budget will have on the disability delivery system.

9. SCDD PAID INTERNSHIP PROGRAM (PIP) EXPERIENCE

Brandi Halstead, Outreach Coordinator Intern for SCDD’s San Bernardino Regional Office, shared her experience with the Paid Internship Program (PIP). Interning with SCDD has helped her to develop advocacy skills and connect with other advocates in the region. Through her position, Ms. Halstead has provided trainings on emergency preparedness, attended outreach events, and gained office skills. Ms. Halstead would like advocates who are interested in getting a job to know that it is ok to ask for support, including requesting a job coach.

10. OVERVIEW OF SCDD STORYTELLERS BLOG

Michelle Cave, SCDD Communications Manager, provided the Committee with an overview of the SCDD Storytellers Blog and encouraged members to take a look at the digital space and share their thoughts and feedback with staff.

11. PLANNING FOR 2023 – 2024 SAAC ACTIVITIES

As a follow-up to the November 2023 meeting, members shared that early identification, marriage penalty for benefits, and helping advocates participate in advocacy are some of the issues that affect them personally. Marriage penalty for benefits, access to education, housing access, and helping others participate in advocacy activities were mentioned as issues for their community/region, and marriage penalty for benefits and access to education were identified as statewide issues.

Legend:

SA = Self-Advocate

FA = Family Advocate

DRAFT

Additionally, members shared that they would like the Committee to create plain language guidance for medical professionals, be a part of the effort to get rid of the marriage penalty for Social Security/Disability benefits, invite representatives from the field of education to talk about methods used to educate children with disabilities, advocate for better access to medical services for people with I/DD, develop trainings, and educate professionals on the needs of people with disabilities.

12. ADJOURNMENT

The meeting was adjourned at 3:30 P.M.

Legend:

SA = Self-Advocate

FA = Family Advocate

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MARCH 18, 2024
AGENDA ITEM 6
INFORMATION ITEM

SELF-ADVOCATES ADVISORY COMMITTEE
STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Emerging Issues and Concerns

Each member will have a chance to give updates on local and regional concern(s) for people with intellectual and developmental disabilities (I/DD). Updates may include:

- A. Updates/concerns from Regional Advisory Committees
- B. Regional emerging issues or barriers to self-advocacy
- C. Recommendations for future meetings and/or projects and activities

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MARCH 18, 2024

**AGENDA ITEM 7
INFORMATION ITEM**

**SELF ADVOCATES ADVISORY COMMITTEE
STATE COUNCIL ON DEVELOPMENTAL DISABILITIES**

SSAN Report

SCDD SSAN Representative will provide a verbal report of the February SSAN Meeting.

Handout

- February 2024 SSAN Report

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MARCH 18, 2024
AGENDA ITEM 8
INFORMATION ITEM

SELF-ADVOCATES ADVISORY COMMITTEE
STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Review of Council Business

State Council on Developmental Disabilities staff will review Council business with the Committee. This item may include:

- A. SCDD agency updates
- B. Statewide updates
- C. National updates
- D. Cycle 47 Grant process

Items related to this agenda item can be found in the Council packet.

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MARCH 18, 2024

**AGENDA ITEM 9
INFORMATION ITEM**

**SELF-ADVOCATES ADVISORY COMMITTEE
STATE COUNCIL ON DEVELOPMENTAL DISABILITIES**

The Person-Centered Advocacy Vision Education (PAVE) Project

The Person-Centered Advocacy Vision Education (PAVE) Project is run by the CA Community Living Network (CCLN). CCLN describes the PAVE Project as a project to develop good tools to measure how good peoples' lives are (their outcomes) when they are receiving services. The PAVE Project needs to gather information that helps CCLN understand why some people have better outcomes and others have poorer outcomes.

PAVE is developing a tool to measure services. They started with select services and created 1) plain language definitions, and 2) operational definitions of those services. These include attached descriptions of:

- Supported Living Services (SLS)
- Independent Living Services (ILS)
- Supported Employment Services (SES)
- Respite

PAVE would like SAAC's review and feedback on both the plain language and operational definitions of these services. The attachments are organized with the original operational resource, followed by the plain language version of the resource. Please review these materials and make note of any suggestions about changes that need to be made relating to language and/or way the information is presented (formatting).

Attachments

- Draft Operational Supported Employment Services (SES) **(separate handout)**
- SES Operational definition Plain Language
- Draft Operational definition Respite **(separate handout)**
- Respite Operational definition Plain Language
- Draft Operational definition Independent Living Services (ILS) **(separate handout)**
- ILS Operational definition Plain Language
- Draft Operational Supported Living Services (SLS) **(separate handout)**
- SLS Operational definition Plain Language

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What would “supported employment services” look like for me?



You can receive supported employment services wherever you live. You can be living independently in your own home, with your family or in a group home.

You don’t have to be able to work full-time. You can receive supported employment services even if you just want to work part-time.

Supported employment services would help you find and keep a job that:

- Is “competitive” means that:
 - Anyone can apply for the job, not just for people with disabilities.
 - You would be paid at least the minimum wage for the State in which you live.
 - You would be paid the same wage as people without disabilities working in the same job.
 - You would receive the same employment benefits as people without disabilities working in the same job.
- Is “integrated” means that:
 - You would work in the same workplace as people without disabilities.
 - You would NOT work in a setting that is just for people with disabilities.

You may receive support from one person or from several different people, depending on what support you need and how the services are organized. The person might be called a “job developer”, a “job coach” or an “employment specialist”.

They will help you find a job. For example, they will:

- Find out about you, your skills, interests and the support you might need to work.
- Find out what are your goals and dreams for work.
- Help you to work out what job might be best for you and what you would like to do.
- If you are not sure what job you would like, they will help you get experience of different jobs, so you have more information to help you decide.
- Contact different employers to find jobs that match your skills and interests and employers that will support you to do the job.
- Support you to apply for a job.
- Help you prepare for an interview and to get to an interview if needed.

They will support you:

- to develop the skills you need to do the job. This might include skills related to the work itself. It might also include skills and support related to working with other people and as part of a team.
- to understand other things you might need to do in order to get a job and to keep it – this might include things like:
 - how to dress for your job,
 - transportation to get to work,
 - how to make sure you have taken your medicine
 - how to access health care or therapies that will make sure you can do the job.
- to understand how having a job will impact on your disability benefits.
- to understand how you will be paid
- to understand who you will need to tell that you have a job.

They would also:

- Help your employer to adapt any tasks or the environment so that you can do the job.
- Help your family or other people who support you to know how they can help you to get and then keep your job.

Once you start your job, your job coach will:

- Spend as much time as you need supporting you to do the job and becoming as independent as possible at work.
- Support you to build relationships with the people you work with.
- Help those who work with you to understand how they can also support you to do the job well.
- Advocate for you and support you if you need to talk to people you don't know very well or if there are issues or problems.
- Support you to apply for promotion.
- Support you to find a new job if needed.
- Support you or your legal representative to understand your employment benefits and to plan for future jobs and also for retirement.



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What would “in-home respite” look like for me?



- Someone who does not normally provide my support would come to my home.
- They would support me when my family can't provide my support. For example, this might happen:
 - If they are ill or need to go to hospital.
 - If they need a break
 - If they need to help someone else in the family
- It is usually just for a short period of time.
- Usually, I will be involved in planning my respite service. But if it is an emergency, it might happen quickly.
- Before they support me, the staff will read my plans and information about what I need and what is important to keep me safe and well.
- They will also listen to me and my family to find out how I like my support and what is important to me. Together we will talk about what I would like to do during the time they are working with me.
- The person who comes will generally support me to do all the things that I normally do. If there is something I would rather wait to do when my family return, that is ok.
 - They will support me to stay well and safe. They will support me to eat and drink well, take my medication, be active and feel clean and comfortable.
 - They will support me to do the things that make me happy and help me feel relaxed and calm.

- They will support me to take part in activities that help me learn and take-part in the community.
- They will support me to keep connected with my family and friends.
- They will support me to take part in religious or cultural events or activities that I wish to do.
- If I work, they will help me get ready for work and ensure I get there and home safely.
- If I go to school or college
- In all of the areas above:
 - they will support me to be as independent as possible but will provide the support I need to make sure things go well.
 - They will follow my chosen daily routine – e.g. support me to get up, go to bed, eat and drink at the times I wish to do so.
 - They will use the method of communication that works best for me.
 - They will treat me and my family with respect.
 - They will respect my home and the things in my home that are important to me.
 - They will make sure I have the privacy I need during personal care.
 - They will arrive on time to provide my support.

What would “independent living services” look like for me?

Independent Living services would support you to ***work towards the goal of living “independently”***.

Living independently means that you would:

- Live in a home that you rent or own – a home that you have chosen to live in. You can either live on your own or with someone else that you chose to live with.
- Be responsible for:
 - Paying your bills and managing your money.
 - Looking after your home, for example, making sure it is clean and that things that are broken get fixed. Decorating your home.
 - Looking after yourself and others who depend on you – for example, children or pets. This would include things like personal care (washing and dressing, looking after your teeth and hair, shaving), doing laundry, shopping, planning and cooking meals.
 - Keeping yourself safe at home and in the community
 - Looking after your health – making and going to doctor’s appointments, getting your medication etc.
- Be able to do many of the things above for yourself over time.

To live independently, you don’t have to be able to do everything yourself – for example, you can arrange for someone else to come and clean your house if you are not able to do this for any reason.

You can have a personal assistant to help you with personal care. You can also have support from people who are not paid – your family and friends for example.

You can have technology to help you with all of these things.

However, when you are living independently it is YOU who decides about this, and you are involved in organizing it.

If you receive Independent Living Services (ILS) you will have an ILS instructor. They will support you to learn the skills you need to live more independently. They will talk to you and observe what you can already do and then work with you to plan your ILS program. It might take you just a short time to learn what you need to be independent, or it might take a long time. Taking a long time is ok.

Your ILS instructor can help you:

- find a house to live in
- understand the rental agreement you need to sign and what you need to do to be allowed to stay living in that home – such as paying your rent and bills, looking after the house, etc.
- find people to share your home with if you need or want to do that

However, Independent Living services should help you have *a good life* in the community – not just have *a house* in the community. As well as helping you learn the skills you need to look after yourself and your home, your ILS instructor can also support you to:

- access all the benefits available to you.
- know the area where you live and be able to travel where you need to go.
- connect with people in your community.
- access activities and events that you are interested in.
- gather the information you need to make decisions about what you do.
- speak up for yourself and communicate with others.
- find technology and set up your environment to help you be as independent as possible.
- be safe in your relationships and when out and about in the community.
- access opportunities for education and for work experience.
- identify people in your neighborhood who you can ask for help if necessary.
- access therapy or treatments that might help you to be more independent.
- Identify things you can do if you feel sad or angry or lonely.

You can start to work towards independent living even when you live with someone else like your parents or another relative or are living in a group home or receiving supported living services. Even after you move into your own home,

you can have help to learn more skills and can have support from other services which can be reduced over time as you become more independent.

Your ILS instructor will also support you to stay as independent as possible in your own home for as long as possible and as you get older. They can help you if your needs change – for example, they can help you to learn new skills or to apply for other services and support. Sometimes people forget skills they learnt when they were younger – ILS services can help you re-learn skills you might have forgotten.

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What would “supported living” look like for me?

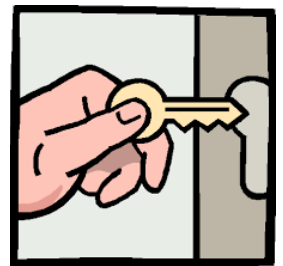
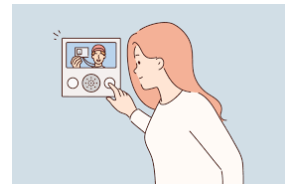
With the help of supported living services, I would have:

A home of my own

I would....

- live in a home that is in the community and is like the homes that people without disabilities live in.
- live in a home that allows me to easily access all the facilities and activities available in the community.
- choose where I live.
- choose who I live with.
- have my name on a document that says this is my home and allows me to stay there.
- be able to stay in my home for as long as I want even if my needs change or the organization providing my support changes.
- be able to move house and sell get support.
- Be able to freely move around my home and access all areas of my home.
- Have a private space and somewhere to keep my important things, even if I share with other people.
- Feel safe in my home and neighborhood.
- Have a key to my home and use it, with as much support as I need to do this.
- Answer the door and phone, if I have one, with as much support as I need to do this.
- Open my mail, with as much support as I need to do this.
- Contribute to the cost of the rent or mortgage payment.
- Look after my home, with as much support as I need to do this – for example, pay my bills, clean my house, look after my yard if I have one, etc.
- Have a say in where things are stored, how the home is decorated and how and when things happen around the home.

MY HOUSE



- Have a say in who can come into my home and when etc.
- Be supported by staff who respect me, my home and my belongings.

Choice and control

I would....

- Have the opportunity to have new experiences and to learn new skills, with as much support as I need to do this
- be making choices every day, with as much support as I need to do so – choosing what I eat and drink, how and where I spend my time, what I wear, how I look
- Be deciding how things happen in my home – when things happen, in what order, where, and who I do things with.
- Communicate with my support staff in my own language or with my own form of communication way and they would listen and respond
- be involved in bigger decisions about my life – for example, decisions about where I work, how long I go to work for, school or college, how to spend my money, where to go on holidays, what clubs or activities to participate in, etc.
- Be involved, as much as I want to be, in decisions related to my services and in recruiting and choosing my support staff.
- Be involved, as much as I want to be, in meetings about me and my services
- Be able to say what I would like to do in the future and set goals related to what is important to me.
- have one or more people who I trust to help me to make decisions and think about what I want to do in the future.
- Be supported by staff who do things my way as much as possible, rather than making me do things their way.



Relationships

I would..

- have contact with my family and friends as much as I want and is possible for me to have.



- Be able to have family and friends come and visit me
- Be able to go out with my family and friends to activities and events
- Be supported to have good relationships with my neighbors and other people in my community
- Be supported by staff who are kind, respectful, positive and encourage me.



Community Membership

I would....

- Be taking part, with as much support as I need, in the same activities and events and going to the same places in the community as people without disabilities, based on my needs, preferences and interests.
- Be working in jobs or volunteering alongside people without disabilities, with the support I need to be successful.
- Doing things to help other people or helping in my community in some other way.



Flexible, Tailored Services and Supports

I would...

- Receive support that is based on an assessment and plan that I have been involved in.
- Receive support that has been designed around *my* needs, preferences and goals.
- Be supported by staff that do things **with** me and not just *to* me or *for* me.
- Be supported by staff who Understand my needs and the way I like and need my support
- Receive support that meets me where I am today and changes as my needs and preferences change.



- Be seen as an individual and not just someone with a disability who receives services.
- Be supported to succeed, learn and feel good about myself.
- Be supported to be as independent as possible to receive as much support as I need to have a good quality of life.



MARCH 18, 2024

**AGENDA ITEM 10
INFORMATION ITEM**

**SELF-ADVOCATES ADVISORY COMMITTEE
STATE COUNCIL ON DEVELOPMENTAL DISABILITIES**

Developmental Disabilities Awareness Month Discussion

Since 1987, the month of March has been recognized as Developmental Disabilities Awareness Month (DDAM). In recent years, the National Association of Councils on Developmental Disabilities (NACDD) has partnered with the Association of University Centers on Disabilities (AUCD) and National Disability Rights Network (NDRN) to create a social media campaign that highlights the many ways in which people with and without disabilities come together to form strong, diverse communities.

In preparation for this agenda item, please take a moment to review the [NACDD Developmental Disabilities Awareness Month Webpage](#) and think about the kind of opportunities SCDD creates for people with Intellectual and Developmental Disability (I/DD) in California and how SCDD can increase the number of available opportunities .

Attachments

- Developmental Disabilities Awareness Month Information Sheet

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History Behind Developmental Disabilities Awareness Month

In 1987, President Ronald Regan proclaimed March as ‘Developmental Disabilities Awareness Month.’ The Developmental Disabilities Awareness Month shines a spotlight on the disabled community and demonstrates how people with developmental disabilities live normal lives. In turn, the public can learn how they can help people with developmental disabilities achieve their dreams.

During the month of March, the National Association of Councils on Developmental Disabilities (NACDD) partners with the Association of University Centers on Disabilities (AUCD) and the National Disability Rights Network (NDRN) to create a social media campaign to highlight the many ways in which people with and without disabilities come together to form strong, diverse communities.

The theme for this year’s campaign is ‘A World of Opportunities.’ People are encouraged to share stories about the lives of people with I/DD and resources available to help them live the lives they choose. People can use #DDAM2024, #DDAwareness2024, #NewOpportunities, or #AWorldofOpportunities to tag their content on social media.

In California, the term ‘developmental disabilities’ is identified as a disability that begins before a person is 18 years old, is expected to last for their entire life, and severely limits their ability to carry out activities of daily living, such as those related to self-care, receptive and expressive language, learning, mobility, and/or self-direction. The following are those disabilities or conditions that are included within the definition of a developmental disability (Welfare and Institutions Code §4512[a]):

- Intellectual Disability
- Autism Spectrum Disorder (ASD)
- Cerebral Palsy (CP)
- (Uncontrolled) Epilepsy, and
- Other related conditions or disabilities that significantly impact a person’s ability to carry out 2 or more major life activities (e.g. self-care, mobility, communication, etc.)

The Centers for Disease Control (CDC) published data from a study showing that about 1 in 6 children are identified as having some type of developmental disability.

The State Council on Developmental Disabilities joins with the rest of California to celebrate March as the Developmental Disabilities Awareness Month.

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MARCH 18, 2024
AGENDA ITEM 11
INFORMATION ITEM

SELF ADVOCATES ADVISORY COMMITTEE (SAAC)
STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Adjournment

The next committee meeting is scheduled for May 20, 2024.

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