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MEETING PASSWORD: **074374**

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STATE COUNCIL ON DEVELOPMENTAL DISABILITIES SELF-ADVOCATES ADVISORY COMMITTEE MEETING

POSTED AT: www.scdd.ca.gov

DATE: November 29, 2021

TIME: 2:00 P.M. until 5:00 P.M.

PRESIDING OFFICER: Rosie Ryan

Item 1. CALL TO ORDER

Item 2. WELCOME AND INTRODUCTIONS

Item 3. ESTABLISH QUORUM

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 three minutes to speak.

Item 5. CHAIR REPORT AND ANNOUNCEMENTS

- A. Chair Report
- B. Online Meeting Etiquette
- C. Meeting Ground rules

Item 6. APPROVAL OF SEPTEMBER 13, 2021 MINUTES **Page 7**

Item 7. REVIEW OF COUNCIL BUSINESS **Page 13**

Presented by: SCDD Executive Director Aaron Carruthers

- A. SCDD Agency Update
- B. Review of Council Agenda

ITEMS RELATED TO COUNCIL BUSINESS ARE INCLUDED IN THE COUNCIL PACKET

Item 8. SAAC RECOMMENDATION ON SCDD SSAN REPRESENTATIVE **Page 15**

Presented by: SCDD Self-Advocacy Coordinator, Riana Hardin

Item 9. SAAC FEEDBACK ON SELF-DETERMINATION TRAINING MODULE **Page 19**

Presented by: SCDD Staff

Item 10.	MEMBER UPDATES	Page 55
	A. Updates/Concerns from Regional Advisory Committees	
	B. Emerging Issues	
	C. Barriers to Self-Advocacy	

Item 11.	SAAC RECOMMENDATIONS TO THE COUNCIL	Page 57
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Item 12.	COMMITTEE UPDATES	Page 59
	A. Executive Committee	
	B. Employment First Committee	
	C. Legislative and Public Policy Committee	
	D. State Plan Committee	
	E. Statewide Self-Determination Advisory Committee	

Item 13.	ADJOURNMENT	
	Next Meeting: January 24, 2022	

Accessibility

Pursuant to Government Code Sections 11123.1 and 11125(f) and Executive Order N-29-20 (This Executive Order can be found by clicking the link on page one of the agenda, or by typing <https://www.gov.ca.gov/wpcontent/uploads/2020/03/3.17.20-N-29-20-EO.pdf> into your web browser), individuals with disabilities who require accessible alternative formats of the agenda and related meeting materials and/or auxiliary aids/services to participate in this meeting should contact Riana Hardin at (916) 263-8196 or Riana.Hardin@scdd.ca.gov. Please provide at least 3 business days prior to the meeting to allow adequate time to respond to all requests.

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

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NOVEMBER 29, 2021
AGENDA ITEM 5
INFORMATION ITEM

SELF-ADVOCATES ADVISORY COMMITTEE
STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Chair Report and Announcements

Presiding Officer Rosie Ryan will provide an update and SCDD staff will lead a discussion with the Committee regarding online meeting etiquette and why it is an important part of having a successful meeting. The presenters will provide ground rules to help facilitate open and respectful meetings and talk about helpful tools, such as Robert's Rules of Order.

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NOVEMBER 29, 2021

AGENDA ITEM 6

ACTION ITEM

SELF-ADVOCATES ADVISORY COMMITTEE

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Approval of September 13, 2021 Minutes

Action Recommended

Approve the September 13, 2021 SAAC Minutes

Attachments

September 13, 2021 SAAC Minutes

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**SELF-ADVOCATES ADVISORY COMMITTEE MEETING MINUTES
SEPTEMBER 13, 2021**

Members Present

Nicole Adler (SA)
Sandra Aldana (SA)
Jeana Eriksen (SA)
Julio Garnica (SA)
Matthew Lagrand (SA)
Maria Marquez (SA)
Kara Ponton (SA)
Rosanna Ryan (SA)
Wesley Witherspoon (SA)

Others Attending

Rihana Ahmad
Aaron Carruthers
Riana Hardin
Beth Hurn
Bridget Kolakosky
Robin
Charles Nguyen
MaryAgnes Nolan
Nicole Patterson
Yaritza Sanchez
Chris Snyder

1. CALL TO ORDER

Committee Chair Jeana Eriksen called the meeting to order at 2:00 P.M.

2. WELCOME AND INTRODUCTIONS

Committee members and others in attendance introduced themselves.

3. ESTABLISHMENT OF QUORUM

A quorum was established.

4. PUBLIC COMMENT

There was no Public Comment.

Legend:

SA = Self-Advocate

FA = Family Advocate

DRAFT

5. CHAIR REPORT AND ANNOUNCEMENTS

Committee Chair Jeana Eriksen reviewed Zoom operations and etiquette and asked members to be patient and kind with one another.

6. APPROVAL OF JULY 26, 2021 MINUTES

Members reviewed the minutes from the July 26th meeting. The minutes can be found starting on page 5 of the September SAAC packet.

ACTION 1

It was moved/seconded (Witherspoon [SA]/ Adler [SA]) and carried to approve the July 26th minutes as presented. Motion Passed without objection.

7. REVIEW OF COUNCIL BUSINESS

In preparation for the September Council meeting, SCDD Executive Director Aaron Carruthers provided members with an overview of the agenda for the Council meeting and an update on the logistics for the next day's Zoom meeting which will be a Zoom Webinar format. Executive Director Carruthers talked about how the Governor Recall Election has impacted the operations of SCDD and recent changes to the SCDD budget. Executive Director Carruthers let members know that the legislature passed legislation to extend virtual meetings for boards through the end of 2021.

8. SAAC RECOMMENDATIONS ON COUNCIL BUSINESS

Following discussion about Council agenda items, SAAC members chose to make the following recommendation to the Council regarding the 2022 Policy Priorities:

ACTION 2:

It was moved/seconded (Aldana [SA]/ Witherspoon [SA]) to recommend the Council adopt the Legislative and Public Policy Committee's Recommendations on the 2022 Policy Priorities. Motion passed without objection.

Legend:

SA = Self-Advocate

FA = Family Advocate

Page 2

DRAFT

9. SAAC FEEDBACK ON INTRODUCTION TO LEGISLATIVE PROCESS INFORMATIONAL MATERIALS

Bridgette Kolakosky, SCDD Deputy Director of Policy and Public Affairs reviewed a draft of the SCDD “How an Idea Becomes a Law” training and asked for feedback on the language of the materials. Feedback included: balance graphics with words, use fewer words, use as much plain language as possible, record a voice over for the PowerPoint, and increase font size. Deputy Director Kolakosky also asked for feedback on the Flyer and survey for the “There Should Be a Law” Contest. The survey is available at <https://bit.ly/BillIdeas>.

10. MEMBER UPDATES

Members provided updates and discussed issues and concerns from their communities. Members mentioned an inconsistency in vaccination and mask requirements for in-person education at colleges and universities. Members Expressed concern about the inconsistency in access to the Self-Determination Program between different regional centers.

Members discussed the ongoing issue of caregivers and healthcare professionals experiencing burnout.

11. COMMITTEE UPDATES

Committee members shared updates from other Council Committees and were referred to the committee reports included in the September Council Packet.

12. SSAN REPORT

Councilmember Lagrand provided members with an update on the Statewide Self-Advocacy Network.

13. ADJOURNMENT

The meeting was adjourned at 5:04 P.M.

Legend:

SA = Self-Advocate

FA = Family Advocate

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NOVEMBER 29, 2021
AGENDA ITEM 7
INFORMATION ITEM

SELF ADVOCATES ADVISORY COMMITTEE
STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Review of Council Business

State Council on Developmental Disabilities Executive Director Aaron Carruthers will review Council Business with the committee. This item may include:

- A. SCDD Agency Updates
- B. Review of Council Agenda items

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

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NOVEMBER 29, 2021

AGENDA ITEM 8

ACTION ITEM

SELF ADVOCATES ADVISORY COMMITTEE

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

SAAC Recommendation on SCDD Representative to SSAN

The Statewide Self-Advocacy Network (SSAN) is a cross-disability training network and project of the State Council on Developmental Disabilities (SCDD). SSAN works to promote leadership and build bridges that strengthen advocacy among disability communities by focusing on policy change.

SCDD has a standing seat on SSAN and the SCDD SSAN Representative position is currently vacant. Section 2.4 E of the Council Bylaws gives SAAC the ability to nominate a standing representative to SSAN. By selecting a new SCDD Representative to SSAN, SAAC could provide an additional opportunity for leadership development for Self-Advocates serving on the Council.

Recommended Action:

Select the next SCDD Representative to SSAN

Attachments:

SSAN Flyer

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Statewide Self–Advocacy Network



SSAN Mission Statement

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

WHO WE ARE:

The Statewide Self–Advocacy Network (SSAN) is a cross-disability network in California established in 2012.

WHAT WE DO:

- Develop the knowledge and skills to make a difference in our region and state
- Speak up for all people with disabilities
- Learn about and advocate for issues important to all people with disabilities
- Lead regional and statewide advocacy groups and networks
- Train advocates in their communities in order to grow the Self-Advocacy movement in California
- Share information about programs and supports for people with disabilities

Statewide Self-Advocacy Network



The SSAN partners include:

- State Council on Developmental Disabilities (SCDD) and Representatives from its 12 regional offices
- Association of Regional Center Agencies (ARCA)
- California Foundation for Independent Living Centers (CFILC)
- Department of Developmental Services (DDS)
- Disability Rights California (DRC)
- University Centers for Excellence in Developmental Disabilities (UCEDD: USC Children's Hospital; UCLA Tarjan Center; and UCD M.I.N.D. Institute)

Member Responsibilities

- Share and exchange information with other SSAN members
- Provide information and outreach in the community
- Be a resource for local advocacy groups
- Provide information to local communities
- Promote legislative and policy change
- Provide support and training to local self-advocacy groups
- Participate in SSAN workgroup meetings

For more information, check out www.scdd.ca.gov/selfadvocacy or contact the SCDD Self-Advocacy Coordinator at 916-263-8196.

NOVEMBER 29, 2021

**AGENDA ITEM 9
INFORMATION ITEM**

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

SAAC Feedback on Self-Determination Materials

The Self-Advocates Advisory Committee serves to advise the Council as a voice for all Californians with intellectual and/or developmental disabilities, by promoting State Council participation and peer advocacy that advances independence and inclusion. Section 2.4 D of the Council Bylaws gives SAAC responsibilities that include reviewing meeting materials and other Council produced materials to evaluate and make recommendations regarding plain language approaches.

During the development of the 2022–2026 State Plan, SCDD Staff were organized into groups based on subjects of interest and expertise in order to concentrate on the development of in-depth content in each subject area. These workgroups are referred to as Disability Expert Advisory Panels (D.E.A.P.s). The Self-Determination DEAP would like SAAC members to provide feedback on training materials for the Self-Determination Program.

Please take the time to carefully review materials attached to this agenda item in order to participate in an active conversation and provide feedback on the plain language and accessibility of the attached curriculum.

Attachments:

SCDD Self-Determination Program Overview PowerPoint

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SELF-DETERMINATION OVERVIEW

OR

*How you can have more control in
your life!*



What is Self-Determination?

- ▶ In a nutshell, Self-Determination gives people with disabilities, along with freely chosen family and friends, the ability to:
 - ▶ Plan their own lives
 - ▶ Identify services and supports they want
 - ▶ Use their individualized budget to hire people to assist in implementing the IPP (Individual Program Plan)
 - ▶ Have control



MY
GREAT
AMBITION
IS
TO SECURE
A
SPEAKING PART
IN
MY OWN LIFE.

Gallagher, Bullseye

History and Background

- ▶ The Lanterman Act lays the ground work for self-determination
- ▶ 1998 Self-Determination Pilots started at 5 Regional Centers
- ▶ Significant grassroots effort by consumers, families and advocacy groups to pass a law to expand Self-Determination to include additional participants
- ▶ Senate Bill 468 established the Self-Determination Program in law, including five principles to guide the program
- ▶ On June 7, 2018, the Application for federal funding for the Self-Determination Program was approved by the Centers for Medicare and Medicaid Services (CMS)

Principles of Self-Determination

Freedom
Authority
Support
Responsibility
Confirmation

FREEDOM

- ▶ The right to plan your own life and make your own decisions
- ▶ To choose who helps you
- ▶ To control the services, supports or resources you use
- ▶ To select your providers and change when needed

AUTHORITY

- ▶ To have control over a budget for services
- ▶ To be the employer
- ▶ To set your own standards for services and supports
- ▶ To make your own decisions

SUPPORT

- ▶ To pick the supports and people that help you live, work and play
- ▶ To be successful and productive in the life you choose
- ▶ To make decisions and plan your own life
- ▶ To be a valued member of your community
- ▶ To create a network of friends, family, professionals, community members and others that you choose to help you

RESPONSIBILITY

- ▶ For making decisions in your life and accepting responsibility for those choices and decisions
- ▶ For developing your talents and gifts and for being as productive as possible, including earning income if you are able
- ▶ For contributing back to others and your community
- ▶ For accounting for the wise spending of your funding

CONFIRMATION

- ▶ YOU are the decision maker in your life
- ▶ Be leaders in working within the system as partners
- ▶ Let others know how Self-Determination can work better for people in the future

Learn More About Self-Determination

- ▶ <https://youtu.be/E5nsK9je-nA>
- ▶ (this would be a good place to insert testimonials from individuals CURRENTLY receiving SD services)

Who Can Participate in Self-Determination?

- ▶ If you are over the age of three and receive services from a regional center, you are eligible to participate in Self-Determination
- ▶ You must live at home or in the community
- ▶ You will be expected to attend a training to learn about Self-Determination, and agree to work with a Fiscal Management Service
- ▶ If you live in a licensed, long-term health facility such as a developmental center or an Intermediate Care Facility, you are not eligible unless you are in the process of moving into the community

STEPS TO SELF-DETERMINATION

- ▶ The first and most important step to leading a self-determined life is to create a *Person Centered Plan*
- ▶ You can hire someone to help with this or you can gather your friends and family and create your own plan
- ▶ There are many resources available to guide you in this process through your Regional Center, Department of Developmental Services webpage, your nearest State Council office, You Tube videos, or Google

Person Centered Planning

By keeping you at the center of planning through this process, you will:

1. Identify your hopes and dreams
2. Identify what you like and what you are good at
3. Identify and set meaningful goals for your life
4. Choose who will provide services and supports to help you meet your goals

Person Centered Planning

- ▶ What you want people to know about you
 - ▶ What is important TO you
 - ▶ What is important FOR you
 - ▶ What kind of support will help you
 - ▶ Action plan to achieve your goals
-
- ▶ The Person Centered Plan is used to develop your individual program plan, or IPP

Important TO and FOR You

What is Important TO Me

Living in my own home
Attending sporting
events
Having money to go on
dates
Enjoying my hobbies

What is Important FOR
Me

Having money for bills
and food
Not inviting strangers to
live with me
Advocating for the life I
want to live

Next Step: Your Budget

- ▶ Your Individual Budget is based on how much was spent on services over the last 12 months
- ▶ You decide what services and supports you will spend your money on
- ▶ If you want to make changes to your budget later on, you can move 10% from one category to another
- ▶ Your budget will pay for a Fiscal Management Service, and an Independent Facilitator if you want to use one

Fiscal Management Service

- ▶ You ***must*** use a Fiscal Management Service to be in Self-Determination
- ▶ Receives the money from your budget to make payments to service providers
- ▶ Keeps track of services provided
- ▶ Maintains financial records
- ▶ Takes care of taxes, Workers Compensation, liability insurance, and makes sure all provider legal requirements are met (licenses and certifications)

Cost of Fiscal Management Service

- ▶ The cost of a Fiscal Management Service is based on Department of Developmental Services statewide set rates depending on service and quantity of bills. There are three models that you can select:
 1. Bill Payer
 2. Co-Employer
 3. Sole Employer

Independent Facilitator

Who is an independent facilitator?

A person who can help you implement your program

They **CAN** help you:

- ▶ Make informed decisions regarding your individual budget
- ▶ Locate, access and coordinate the services and supports in your IPP
- ▶ Identify your needs and finding options to meet those needs
- ▶ By leading, participating in and/or advocating on your behalf during the person-centered planning process and when you develop your IPP

Independent Facilitator

The Independent Facilitator *MUST*:

Receive training on the principles of Self-Determination

NOT provide any other service to you

The Independent Facilitator *CAN*:

Be paid from your spending plan if hired

Be a Service Coordinator

Be a family member

The Independent Facilitator is NOT REQUIRED

Traditional Service vs. Self-Determination

Traditional Request

- ▶ Melissa asks for ABA for 10 year old son
- ▶ Regional Center says ABA cannot be provided to anyone over 6 years old
- ▶ Melissa goes to fair hearing
- ▶ One year after request, she wins hearing

ABA Started

Self-Determination

- ▶ Melissa puts ABA therapy into her son's Person Centered Plan
- ▶ Melissa contracts with preferred provider
- ▶ ABA therapy starts within a few days
- ▶ Melissa decides when to start fading ABA therapy; keeps for as long as son needs it

ABA Started Immediately

Roles & Responsibilities: Service Coordinator vs. You

Service Coordinator

- ▶ Has a caseload of about 100
- ▶ Has limited authority to approve service requests and must get approval of supervisor for most
- ▶ Must follow strict purchase of service standards that emphasize “cost-effectiveness”
- ▶ Must pursue “generic services” first

Limited Time

You

- ▶ Have a caseload of one
- ▶ Have complete authority and don't have to make requests or get anyone's approval
- ▶ Must make sure there is enough money in your budget for services you want
- ▶ Need to utilize generic services when possible (saves money)
- ▶ Have full responsibility and authority to make the decisions you want

Unlimited Time and Energy

Roles & Responsibilities: Budget

Regional Center

- ▶ Gets money from the Department of Developmental Services (DDS)
- ▶ Money comes for thousands of people to use
- ▶ Must spend taxpayer money wisely and cost-effectively based on needs
- ▶ Must keep records of expenditures for reporting purposes

You and our FMS

- ▶ Your FMS gets the money for your spending plan from the regional center
- ▶ Your money is for the year, and is for you to spend on the services and supports you want
- ▶ Must spend taxpayer money wisely and cost-effectively based on needs
- ▶ Your FMS must keep records of expenditures for reporting purposes

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Unknown Yearly Amount

Yearly Amount Known

Roles & Responsibilities: Service Providers

Traditional

- ▶ Providers are vendored and under the legal and contractual authority of the regional center
- ▶ Must provide services according to regional center policies
- ▶ Rates of payment and hours of service are set by the regional center
- ▶ Providers are forbidden to do things outside the scope of their vendor agreement

Limited Choice

Self-Determination

- ▶ Workers you hire can be vendored or not and are under your legal and contractual authority
- ▶ Workers you hire must provide the type and amount of services you agreed to at the rate of payment you agreed to
- ▶ You have the authority to tailor services and set your own standards

Unlimited Choice

Can I Hire Anyone or Any Company/Agency to Provide my Services and Supports?

There are some requirements:

- ▶ HCBS Final Rule requirements
- ▶ Some services may require specific credentials or qualifications
- ▶ Health and safety needs must be met
- ▶ Background checks are required for anyone providing personal care support, including family members

HCBS Final Rule and Self-Determination

- ▶ The HCBS Final Rule – effective March 17, 2023
- ▶ Requires that places where people receive services (settings) meet the new criteria in order to qualify for funding
- ▶ All Services need to be compliant with the Final Rule
- ▶ Guidance regarding the HCBS Final Rule and SDP Services will be provided by the Department of Developmental Services (DDS)

What the Final Rule Says

- ▶ You can spend time in, and being part of your community
- ▶ You can work alongside people who do not have disabilities
- ▶ You have choices regarding services and support, and who provides them
- ▶ You have control of your schedule and activities

The role of the Regional Center and State Council on Developmental Disabilities

- ▶ The *local* Self Determination Advisory Committee (SDAC)
- ▶ Statewide role of SCDD to promote SDP
- ▶ The *Statewide* Self–Determination Advisory Committee (SSDAC)?

In Other Words

Self-Determination is about people:

- ▶ Having a choice
- ▶ Knowing more about themselves
- ▶ Having dreams and goals and going after them
- ▶ Being in control
- ▶ Making their own decisions
- ▶ Spending money their way
- ▶ Having dignity and respect

Is Self-Determination For You?

- ▶ Requires a lot of responsibility, paperwork, hiring/firing, etc.
- ▶ If something goes wrong with your services, it is up to you to fix it
- ▶ You have to hire your own staff
- ▶ Do you have a complicated life – conflicts with the Regional Center?
- ▶ Do you need or want unique services not typically offered by the Regional Center?

If Self-Determination /s For You

Next Steps

- ▶ Tell your Service Coordinator you want Self-Determination
- ▶ Attend a Self-Determination Orientation
- ▶ With the help of people you trust, develop a Person-Centered Plan (PCP) to identify your dreams and goals
- ▶ Request your budget information, and prepare your individual spending plan to meet your goals
- ▶ Hire a Financial Management Service
- ▶ Hire an Independent Facilitator if you wish

You Are Self-Determined! Now What?

- ▶ Your FMS will help you monitor and manage your funds throughout the year
- ▶ You will develop a new Individual Budget and Spending Plan every year
- ▶ You will work with your Regional Center Service Coordinator and FMS to make changes to your spending plan or budget throughout the year if needed
- ▶ Self-Determination is always voluntary and you may return to traditional services at any time

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NOVEMBER 29, 2021
AGENDA ITEM 10
INFORMATION ITEM

SELF ADVOCATES ADVISORY COMMITTEE
STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Member Updates

Members will have five minutes to provide the committee with updates regarding local and regional issues of concern for people with intellectual and developmental disabilities. Updates may include:

- A. Updates/Concerns from the Regional Advisory Committees
- B. Emerging Issues
- C. Barriers to Self-Advocacy

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NOVEMBER 29, 2021

AGENDA ITEM 11

ACTION ITEM

SELF ADVOCATES ADVISORY COMMITTEE

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

SAAC Recommendations to the Council

This agenda item is for the committee to discuss any recommendations to the Council.

Recommended Action:

None

Attachments:

None

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NOVEMBER 29, 2021
AGENDA ITEM 12
INFORMATION ITEM

SELF-ADVOCATES ADVISORY COMMITTEE
STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Committee Updates

SAAC members will have an opportunity to share any updates from other SCDD Committees. The following committees have met since the September Council meeting:

- Employment First Committee
- Executive Committee
- Legislative Committee
- State Plan Committee
- Statewide Self-Determination Committee

Attachments

None

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NOVEMBER 29, 2021
AGENDA ITEM 13
INFORMATION ITEM

SELF ADVOCATES ADVISORY COMMITTEE
STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Adjournment

The next committee meeting is scheduled for January 24, 2021.

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