

2021 Virtual State Convention

Adapt. Grow. Thrive.

May 5–8, 2021

TheArcOregon.org/Convention





Welcome!

Dear Members, Friends and Supporters of The Arc Oregon,

Thank you so much for joining us in our Annual State Convention! Although we will miss our usual in-person networking experience – a change we have all grown accustomed to in the past year, we are **THRILLED** to have this opportunity to reconnect with you in a virtual, accessible conference format! The Arc Oregon has had an eventful past year, and we look forward to reviewing the highlights of this with you during our event.

Thanks to the incredible work of our Arc Oregon team, we are pleased to offer you a series of engaging workshops focused on resiliency, self-direction, equity, and legislative advocacy; a wonderful representation of what the Arc supports in its mission and related work, locally and nationally.

We look forward to seeing and hearing from you in our 2021 event!

Most Sincerely,

Anna Keenan-Mudrick
The Arc Oregon Board President

Event Overview

Wednesday | May 5

- Behavior Professional Network Event
- Town Hall Event

Thursday | May 6

- Opening Keynote: Alonzo Kelly
- Self-Advocate Panel Discussion
- Breakout Sessions

Friday | May 7

- Seeds of Change Community Conversations
- Lilia Teninty | ODDS
- Breakout Sessions

Saturday | May 8

- Local Chapter Round Table
- The Arc OR Annual Business Meeting

Ongoing

- Access Pre-Recorded Content
- On-demand viewing of “The R-Word”

Meet Our Exhibitors & Sponsors

It is through the generosity of our sponsors and exhibitors that we are able to offer this year's virtual event at no cost to people with IDD and their families. Please support them by visiting our **Virtual Exhibit Hall** online at TheArcOregon.org/Convention/virtual-exhibit-hall.

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RFO-0006 0616

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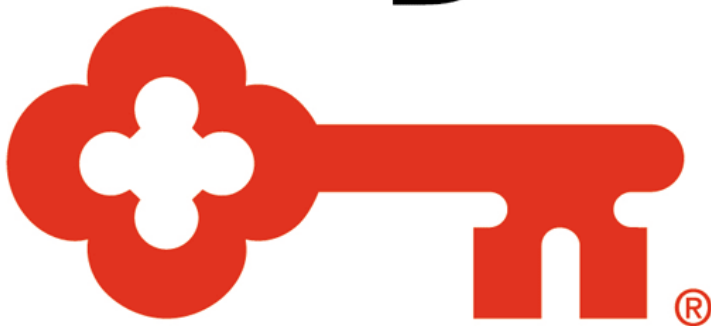
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Attendee Dashboard—[Start Here!](#)

Checkout the Attendee Dashboard each day to find out what's next on the agenda and see daily announcements and updates. Also on the dashboard:

- Request your convention **Swag Bag**
- Complete your **online profile**
- See a list of other **attendees**
- Access all **convention content**

KeyBank



Thanks to Key Private Bank's generous Champion level sponsorship, we can offer FREE registration to self-advocates and family members of a person with IDD!

The Oregon Special Needs Trust program of The Arc Oregon is proud to partner with Key Private Bank for the financial management needs of our trust program, serving more than 700 trust account beneficiaries.

Be sure to visit Key Bank's [Virtual Exhibitor Booth](#) to watch a short video about their services!

Board of Directors 2020-2021

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EDC REPRESENTATIVE

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Kaaren Londahl

DiAnna Hicks-Ross

Join Our Board of Directors!

Are you interested in volunteering at The Arc Oregon and supporting the important work we do ? Well, now is your chance!

Our annual elections will be held on Saturday, May 8, 2021, and we have openings. We will be **accepting nominations from the floor** to fill a **Director** position, which is a 3-year term beginning July 1, 2021.

There is also an opening on our **Board Development (Nominating) Committee**. We are looking for a community member to serve a one-year term to help build our next Board for the 2022 elections.

We also have volunteer openings on most of our **advisory committees**. For more information and to submit an application, visit our website at

TheArcOregon.org/About/Board-of-Directors.

Local Chapters of The Arc

Visit our local chapter websites to learn more about the work each chapter does in its local community.

<p>The Arc of Benton County 928 NW Beca Avenue Corvallis, OR 97330 (541) 753-1711 ArcBenton.org</p>	<p>The Arc of Central Oregon 835 E Hwy 126 Redmond, OR 97756 (541) 548-2611 OpportunityFound.org</p>	<p>The Arc of Curry County Chapter Facebook Page</p>
<p>The Arc of Jackson County 121 N Central Avenue Medford, OR 97501 (541) 779-4520 TheArcJackson.org</p>	<p>The Arc of Lane County 4181 E Street Springfield, OR 97478 (541) 343-5256 ArcLane.org</p>	<p>The Arc of Mid-Columbia (541) 386-3520 Ext 7003 ArcMidColumbia.org</p>
<p>The Arc Portland Metro 6929 NE Halsey Street Portland, OR 97213 (503) 223-7279 TheArcMult.org</p>	<p>The Arc of Tillamook County PO Box 232 Tillamook, OR 97141 TheArcTillamook.org</p>	<p>The Arc of Umatilla County 215 W Orchard Avenue Hermiston, OR 97838 (541) 567-7615 TheArcUmatilla.org</p>

Join Us - Start a New Chapter of The Arc!

If there is no chapter in your area and you are interested in starting a chapter visit TheArcOregon.org to [download our brochure](#) and learn more about how to get started, New chapters may be started from scratch, or an existing nonprofit organization may become an affiliate of The Arc. There is no need to change your organization's name or branding! [Contact us](#) today to find out how to get started on the road to affiliation today!

Town Hall Wednesday May 5th @ 5:00 pm

Please join us for a conversation with Oregon State Legislators about how people with intellectual and developmental disabilities are represented in legislative activities.

Help us welcome Senator Sara Gelser and Representative Rob Nosse, and enjoy this opportunity to ask questions about how the legislature is addressing issues important to people with IDD and their families.

Do you have a question to ask?

Submit your question by May 4th at 5:00 pm, and our moderator will include it in the list of questions to ask our legislators!

[Click here to submit your question.](#)



Photo: Members of The Arc Benton County, The Arc Portland Metro, and The Arc Oregon with Senator Sara Gelser (December 2018)

The R-Word

The R-Word is a film by Amanda Lukoff that unravels the history and lasting effects of the R-word through the lens of the sibling experience. We are very pleased to offer convention attendees the opportunity to screen this film on demand at any time during the convention.

[Click here to watch the film](#)

Please help us thank Guardian Partners for their support of this year's event!

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EDUCATION

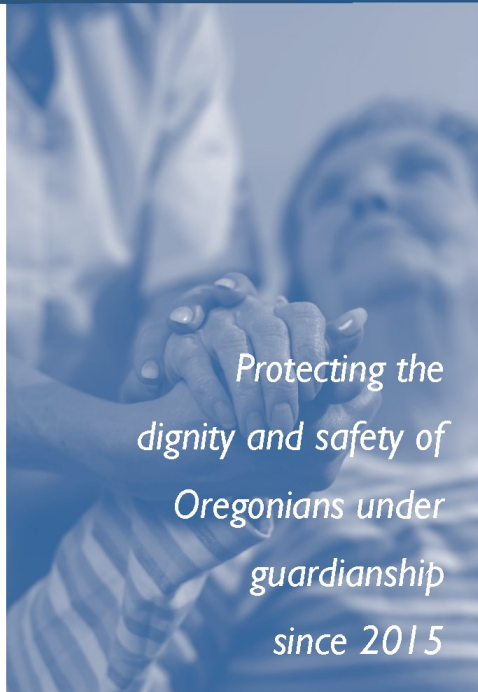
for Guardians of Adults, Guardians of Minors and other fiduciaries.

CASE MONITORING

of guardianships to ensure people with cognitive disabilities are being well cared for.



Guardian Partners is a 501(c)(3) nonprofit.
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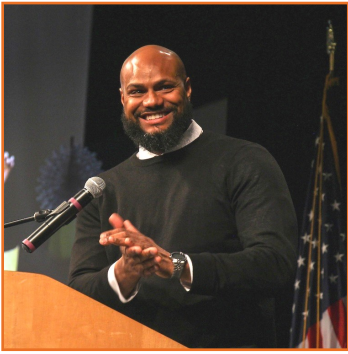
**To discuss bringing Guardian Partners to
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- or -

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Executive Director Marc Kochanski at
marc@guardian-partners.org or
971-409-1358

Keynote Speakers



Alonzo Kelly

A dynamic Executive Coach, Professor, 3x Best Selling Author, and Radio Host, Alonzo Kelly has gained international and global attention as a premier consultant and strategist. Alonzo is recognized as one of the nation's leading experts on leadership development, strategic thinking, planning, and acting which results in individual and organizational goal achievement. He has appeared on America's Premier Experts which airs on major networks across the country including ABC, NBC, CBS, and FOX.

He holds a bachelor's in Accounting, three master's degrees (Public Administration, Human Resource & Labor Relations, Business Administration), and is nearing completion of a PhD in Multidisciplinary Human Services. He is also currently in the process of obtaining his Doctorate in Business Administration.

He currently serves on the State Board of Directors for the ACLU (American Civil Liberties Union), National Board of Directors for SENG (Supporting Emotional Needs of the Gifted), the Fire and Police Commission for the City of Howard, WI, and the Board of Directors for Family Services of Brown County. Learn more at www.alonzokelly.com.

Lilia Teninty

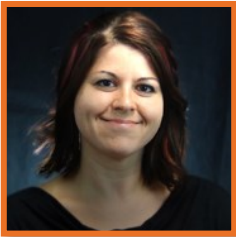
In her role as the Director of the Office of Developmental Disability Services (ODDS) in DHS, Lilia is responsible for the development, oversight and delivery of intellectual and developmental disability services across Oregon.

Lilia brings with her over 13 years of experience, 11 of those working specifically with Intellectual/Developmental Disability (IDD) programs. She has worked in several states, in a variety of roles. She began her career in the field of IDD working for a small non-profit that provided assistive technology to people with disabilities. In 2003 she began working for the State of Indiana, where she supervised the Medicaid waiver unit and moved on to become the Chief of Staff for the Division of Disability and Rehabilitative Services (2006-2007). Lilia later accepted the position of Director of the Division of Developmental Disabilities for the State of Illinois (2007-2011). In 2011 she moved to Oregon to work for the Human Services Research Institute (HSRI). As a Senior Policy Specialist at HSRI, she provided consultation on Medicaid policies and funding mechanisms for people with IDD to several states.

Prior to starting her career, Lilia earned her Bachelor of Arts in International Relations from Mills College and her Masters of Public Affairs from Indiana University. Lilia has a passion for public service and has dedicated most of her career to serving those with intellectual and developmental disabilities.



Meet the Presenters



Aniko Adany
The Arc Oregon
*Person-Centered Practices
Coordinator*
LifeCourse Ambassador



Tamara Bakewell
**Family to Family Health
Information Center**
*Family Involvement
Coordinator*



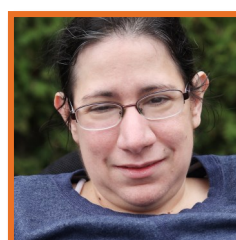
Emily Braman
The Arc Oregon
GAPS Program Director



Cheryl Cisneros
Creating Opportunities
Executive Director



Emily Cooper
Disability Rights Oregon
Legal Director



Jennifer DiBello
The Arc Oregon
Trainer



Alicia DeLashmutt
**Our Home, Inclusive
Community Collaborative**
Founder and President



Cici Gaynor
The Arc Oregon
OSNT Program Director



Jennie Heidrick
The Arc Oregon
OTAC Program Director



Kaellen Hessel
Oregon ABLE Savings Plan
*Advocacy/
Outreach Manager*



Maggie Johnson

Earthtones Northwest
Music Therapy Director



Nicole Jorwic

The Arc US
Director, Public Policy



Nick Kaasa

The Arc Oregon
ISP Trainer
LifeCourse Ambassador



Toni Larson

Residential Facilities
Ombudsman



Kaaren Londahl

The Arc Oregon
Board Member
Self-Advocate



Alan Lytle

The Arc Oregon
Operations Support
Director



Alice Massey

The Arc Oregon
ERC Program Manager



Paula Markovitz
Boga

The Arc Oregon
Executive Director



Kristen McSorley

Earthtones Northwest
Music Therapy Director



Kimberly Taylor

The Arc Oregon
Board Member
Self-Advocate

Read full biographies on all our presenters online at

TheArcOregon.org/Convention/Presenters.

Agenda & Links

Use the Session Links on this Agenda to go directly to the session page on the convention website. You will find a “Join Zoom meeting” button at the bottom of the session page fifteen (15) minutes before the session begins. You can also find handouts and materials.

If you miss a session, a recording will be posted on the session page the following day.

Wednesday, May 5

9:30 am	Pre-Recorded Content Available	Attendee Dashboard
5:00 pm	Town Hall Event Senator Sara Gelser, Representative Rob Nosse	Session Link

Thursday, May 6

9:30 am	Opening Session Welcome: Anna Keenan-Mudrick, President Keynote Speaker: Alonzo Kelly Session Link		
11:00 am	Getting the supports you need to live the life you want Toni Larson RFO Session Link	Music-Empowered Resiliency Kristen McSorley & Maggie Johnson Earthtones Session Link	Policy Update from Washington DC Nicole Jorwic The Arc US Session Link
1:00 pm	Self-Advocate Panel: Creating a Life for Thriving! Jen DiBello, Nick Kaasa, Kaaren Londahl, Kimberly Taylor Session Link		
2:30 pm	More than a Chart: One Page Profiles for the Medical Setting Tamara Bakewell Oregon Family to Family Session Link	Take Control of Your Financial Future with ABLE Kaellen Hessel Session Link	
4:00 pm	Homes Not Housing! Alicia DeLashmutt Our Home Inclusive Community Session Link	Planning for a Health Emergency Tamara Bakewell Oregon Family to Family Session Link	

Friday, May 7

10:00 am	Seeds of Change Community Conversations Emily Braman, Alan Lytle Keynote Address: Lilia Teninty Session Link	
1:00 pm	Access to Health Care During a Pandemic Emily Cooper Disability Rights Oregon Session Link	Tips for Managing In-Home Supports Jennifer Heidrick & Alice Massey The Arc Oregon Session Link
2:30 pm	Exploring and Supporting Communication Aniko Adany & Nick Kaasa, The Arc Oregon Session Link	Tools to Support Decision Making Emily Braman The Arc Oregon Session Link

Saturday, May 8

9:30 am	Local Chapter Round Table Discussions	Session Link
11:00 am	The Arc Oregon Annual Business Meeting	Session Link

Pre-Recorded Content

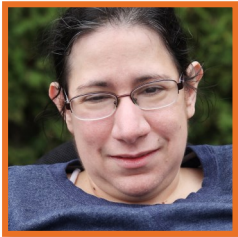
All pre-recorded content will be available by 9:30 am on Wednesday, May 5th. Use the Session Link to view this content anytime through June 30th.

The R-Word A Film by Amanda Lukoff	Session Link
Advocacy Across Systems Cheryl Cisneros, Creating Opportunities	Session Link
Decision Making Supports: Alternatives to Guardianship Emily Braman, The Arc Oregon	Session Link
Understanding How to Establish and Access My Oregon Special Needs Trust Cici Gaynor, The Arc Oregon	Session Link
Embracing Best Practices: Introduction to the Nonprofit Standards for Excellence Paula Markovitz Boga, The Arc Oregon	Session Link

Self-Advocate Discussion Panel

Thursday May 6th @ 1:00 pm | [Session Link](#)

Don't miss this great opportunity to hear from people with intellectual and developmental disabilities share their vision of a good life! Our moderator and Board Vice-President, Jeff Whalen, will ask a panel of four adults with IDD—Jen, Nick, Kaaren, and Kimberly – how professionals, family members, and friends can best support them to Adapt, Grow and Thrive!



Jennifer DiBello

The Arc Oregon
Trainer



Nick Kaasa

The Arc Oregon
ISP Trainer
LifeCourse Ambassador



Kaaren Londahl

The Arc Oregon
Board Member
Self-Advocate



Kimberly Taylor

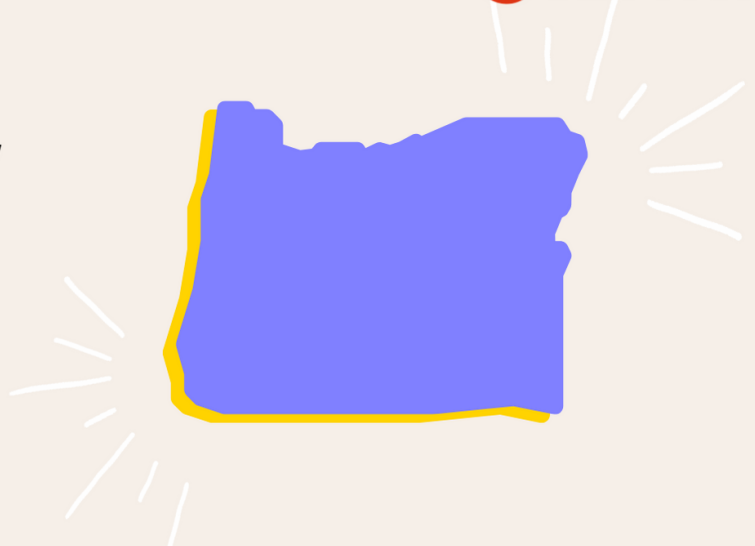
The Arc Oregon
Board Member
Self-Advocate

A Message from our Advocate/Silver Sponsor:

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Session Descriptions

Pre-Recorded Sessions

-
- Anytime** **Decision Making Supports: Alternatives To Guardianship**
Emily Braman
- [Session Link](#) Learn about various decision making supports available for adults with IDD. These supports are alternatives to guardianship that provide a way for an adult to self direct their life while being supported in a manner that works for them. We will explore supports for various areas of life including health care, financial, educational and more.
-
- Anytime** **Advocacy Across Systems** | Cheryl Cisneros
- [Session Link](#) Explore effective strategies to navigate service systems and advocate for yourself or your loved ones.
-
- Anytime** **Understanding How to Establish and Access My Oregon Special Needs Trust** | Cici Gaynor
- [Session Link](#) This session will discuss the requirements for establishing a sub-account within the Oregon Special Needs Trust (whether 1st or 3rd party) and answer the difference between a pooled special needs trust and a private special needs trust (and how ABLE can fit into the mix). We will also explore the process for the uses for the OSNT, the process for requesting funds,.
-
- Anytime** **Embracing Best Practices: Introduction to the Nonprofit Standards for Excellence** | Paula Markovitz Boga
- [Session Link](#) For more than 20 years, hundreds of organizations have used Standards for Excellence® Code to help nonprofits become more sustainable and accountable. Learn how to use the Standards to propel your organization forward in this fast paced, participatory introductory course. The course will provide an overview of the Standards for Excellence 67 performance indicators and give participants an opportunity to assess their own organizations. Attendees will learn how to tap into a complete library of the resources available to nonprofits who wish to use the Standards for Excellence to strengthen their organizations. The concepts covered are relevant to organizations of all sizes.
-

Wednesday, May 5

-
- 5:00 pm** **Legislative Town Hall** | Senator Sara Gelser, Representative Rob Nosse
- [Session Link](#) We will welcome several Oregon legislative representatives to join us for a conversation about how people with intellectual and developmental disabilities are represented in legislative activities.
-

Session Descriptions

Thursday, May 6 – Morning

9:30 am **Opening Session / Keynote** | Alonzo Kelly

[Session](#)
[Link](#)

It Is Not The Map, It's The Terrain That Keeps Us Safe While Navigating Mt. Covid!

I had no doubt we would collectively combine our knowledge and experience to map out a strategy to get us through the perfect storm (Pandemic, New Era Civil Rights Movement, and Presidential Election year). The problems never seem to center on the plan but rather the unanticipated challenges and hurdles along the way. We will give ourselves credit and celebrate our success during these times. We will also explore how to better anticipate and respond to what is yet to come.

11:00 am **Policy Update from Washington DC** | Nicole Jorwic

[Session](#)
[Link](#)

The 117th Congress has a lot to tackle in the face of the continuing pandemic and recovery issues. All of these policy discussions will have an impact on the lives of people with disabilities. This session will outline our legislative priorities for this Congress and the new administration and address where we have made progress and where we are heading.

11:00 am **Music-Empowered Resiliency** | Kristen McSorley, Maggie Johnson

[Session](#)
[Link](#)

Join us for an interactive music-based power jam! No previous experience needed and everyone is welcome to this fun and rejuvenating hour facilitated by Oregon licensed music therapists. Music is particularly powerful in addressing self-care, social connection, and stress-reduction during COVID-19. Access your inner musician through virtual group singing, instrument play, dancing, creating, and breathwork. Shakers, kazoos and other instruments welcome, but not required!

11:00 am **Getting the supports you need to live the life you want**

Toni Larson

[Session](#)
[Link](#)

Your home is your castle. The color you paint your bedroom, what you decide will be on the menu this week and getting together with your friends for bowling practice is only limited by your budget and time you have available and, maybe your painting skills! However, if you are living in a licensed or certified setting with roommates, working with family, support staff, and an ISP team – sometimes it isn't that easy. Let's talk about your rights, how to communicate what you want, and how to quickly find and use resources to help you affect change in your home to live the life you want.

1:00 pm **Creating a Life for Thriving!**

Self-Advocate Panel : Jen DiBello, Nick Kaasa, Kaaren Londahl, Kimberly Taylor

[Session](#)
[Link](#)

During this panel discussion, four self-advocates who experience IDD will talk about what supports they need to create a good life for themselves. This is a great opportunity for friends, family members, and paid providers to hear about what you can do to support the people you love so they can Adapt, Grow, and Thrive in life!

2:30 pm **More than a Chart: One Page Profiles for the Medical Setting** | Tamara Bakewell

[Session](#)
[Link](#)

This interactive workshop will demonstrate how to design a One Page Profile that works especially well in the context of health care. We will demonstrate how to use the tool to build respectful relationships with doctors, therapists, front office staff, and other medical professionals. This session is especially recommended for transition-age, but is appropriate for family members of children and youth of all ages.

2:30 pm **Take Control of Your Financial Future with ABLE**

Kaellen Hessel

[Session](#)
[Link](#)

Is spend down a frequent problem for you? Are you worried that if you work too much and save too much, you'll put your benefits in jeopardy? Wish you could build a nest egg for your kid who has a disability? The Oregon ABLE Savings Plan can help. Learn everything there is to know about the Oregon ABLE Savings Plan including who is eligible, how it works, what you can save for and more.

4:00 pm **Planning for a Health Emergency** | Tamara Bakewell

[Session](#)
[Link](#)

We never know when a call to 911 is in our future. For those whose loved ones experience special health needs, an extra level of planning, is helpful. This workshop will review how to prepare for a health emergency, including steps you can take before, during, and after an emergency. Participants will receive a toolkit with specific steps recommended by EMS and other medical professionals as well as families of individuals with special health needs.

4:00 pm **Homes Not Housing!** | Alicia DeLashmutt

[Session](#)
[Link](#)

There are approximately a million families in the United States, with caregivers over the age of 60, who provide in-home care for an adult family member that experiences IDD. Come learn about one family's quest to provide a replicable example of the kind of home and inclusive community that they searched for as their daughter rapidly approached adulthood, but didn't find. Our Home - Cathedral Park cohousing is intentionally bringing together community members with diverse abilities, ages, and income levels. Come share in the journey that Founder, Alicia DeLashmutt calls, "Over, Under, Around, and THROUGH" as the Our Home community strives to build locally and inform nationally.

9:30 am **Seeds of Change Community Conversations**

[Session](#)

Alan Lytle & Emily Braman

[Link](#)

Join us for our 3rd Annual Community Conversation

10:00 am **Keynote | Lilia Teninty**

[Session](#)

[Link](#)

Lilia Teninty, ODDS Director, will join our Seeds of Change Community Conversation session to provide an update on what's happening at ODDS and how Oregon Developmental Disabilities Services is working to support people with IDD to adapt, grow, and thrive.

1:00 pm **Tips for Managing In-Home Supports**

[Session](#)

[Link](#)

Jennie Heidrick & Alice Massey

Promoting successful working relationships between people, who are aging or children and adults with Intellectual and Developmental Disabilities (I/DD), and the in-home care provider they employ to provide in-home supports is critical! Join us to learn more about the Employer Resource Connection (ERC) program resources and services. We will provide an overview of the tools and supports our consultants can use to assist you, your loved one or person you support with managing their in-home supports.

1:00 pm **Access to Health Care During a Pandemic | Emily Cooper**

[Session](#)

[Link](#)

This year has been a tough year for our entire world. Here, in Oregon, we have learned some critical lessons including that bias against people with disabilities continue to pervade the health care system. We also learned the power of collective movement to ensure our rights are protected.

2:30 pm **Tools to Support Decision Making | Emily Braman**

[Session](#)

[Link](#)

Supported Decision Making is an alternative to guardianship that identifies the supports a person wants to assist them in making decisions about their life. Learn about the values and principles of SDM, the components of support within SDM, and explore tools for helping someone identify the supports that will best help them. This presentation will include discussion time, step by step review of SDM components,, problem solving brainstorm, and listening.

2:30 pm **Exploring and Supporting Communication**

[Session](#)

[Link](#)

Aniko Adany & Nick Kaasa

People communicate in diverse ways. Exploring barriers to understanding and supporting a person's communication can bring about new opportunity and a deeper connection.

Saturday, May 8

9:30 am **Local Chapter Roundtable Discussions**

[Session](#)
[Link](#)

This will be an opportunity for local chapter staff, volunteers, and board members to connect with each other for networking, sharing experiences, asking questions, and discussing specific topics of concern and/or interest.

11:00 am **The Arc Oregon Annual Business Meeting**

[Session](#)
[Link](#)

Everyone is welcome to join The Arc Oregon Board of Directors, staff, and local chapter representatives at our annual business meeting. The meeting agenda includes reports from our President, Executive Director, and Local Chapters, as well as a financial report and Board elections.

A word from our sponsor:

Want a career that makes a difference?



Consider a job working with people with disabilities!

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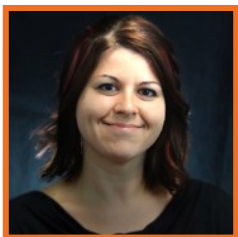
Save the Date!
May 6-7, 2022

We are all looking forward to gathering in person again for our next State Convention!

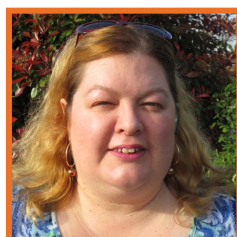
Stay tuned for more information by signing up for our [E-Newsletter](#).


The Arc
Oregon

Meet Our Team!



Aniko Adany
*Person-Centered Practices
Coordinator
LifeCourse Ambassador*



Heidi Barnett
*GAPS Advocate
National Certified Guardian*



Missy Bartolome
*Administrative Services
Manager*



Emily Braman
*GAPS Program Director
National Certified Guardian*



Jenn Buss
*ISP Project Manager
LifeCourse Ambassador*



Cari Davis
*GAPS Advocate
National Certified Guardian*



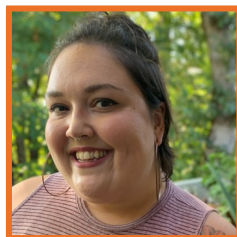
Jennifer DiBello
Trainer



Jessica Dollarhide
OSNT Account Manager



Cici Gaynor
OSNT Program Director



Casiopeia Friberg
*GAPS Advocate
National Certified Guardian*



Jennie Heidrick

*OTAC Program Director
LifeCourse Ambassador*



Susan Hawkins

*Training Coordinator
Digital Marking Coordinator*



Nick Kaasa

*ISP Trainer
LifeCourse Ambassador*



Alan Lytle

*Operations Support
Director*



Paula Markovitz
Boga

Executive Director



Alice Massey

ERC Program Manager



Denise Porter

ERC Consultant



Hanna Royer

Public Policy Intern



Sharyn Smith

ERC Consultant

Our team is here to help!
Contact us at:



TheArcOregon.org



info@thearcoregon.org



503-581-2726

Sarah's Story

In 2020 Sarah was admitted to the hospital for a high fever and diagnosed with pneumonia. The hospital team tried to compel us, as Sarah's legal guardian, to sign a Do Not Resuscitate (DNR) order for her without good cause. Sarah was a young and otherwise healthy woman who led a full and robust life. She was working with a job developer to find employment, she enjoyed going to the salon to have her hair and nails done, visiting with friends, and hanging out at Starbucks to see the people and take in the aromas. She had a dark sense of humor and her laugh and smile could light up a room!

Through conversations with the hospital staff, however, it was clear the medical professionals charged with caring for Sarah did not believe her life was worth saving – because she did not “typically walk and talk,” as one doctor put it. The hospital staff made it clear with their words, actions, and body language, that they did not see any value in the life of a person who uses a wheelchair and non-verbal communication.

In short, Sarah was not afforded the full medical treatment and support during her hospital stay that she was entitled to. We had to fight to have a support person with her to help facilitate communications with hospital staff, and we were forced to justify Sarah's right to standard medical care as well as life-saving treatment. In the end, the hospital failed to provide adequate treatment and failed to communicate a serious change in her condition with her guardian or her support team. This ultimately led to her untimely death and prevented us from being with her in her final hours.

Unfortunately, Sarah's story is not unique. We engage in these types of battles regularly, with or without the threat of a pandemic. We know Sarah would want her story to be told, and we are determined to continue Sarah's fight. We are proud of our work last year in partnership with Disability Rights Oregon and the Oregon Legislature to seek much needed changes in how people with IDD are treated within our medical and other systems. This work resulted in passage of Senate Bill 1606 in the special legislative session, affirming the rights of people with IDD to have the support they need and prevent the type of discrimination Sarah experienced in hospital settings.

We will continue Sarah's fight through ongoing advocacy and education across all systems.



Sarah McSweeney
1975–2020