



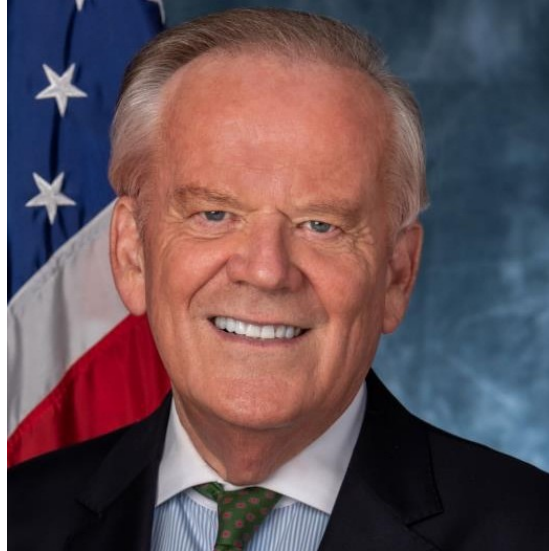
The President's Committee for People with Intellectual Disabilities (PCPID)

Full Committee Meeting

May 1, 2023

12:00 PM to 5:00 PM EST

Call to Order, Welcoming Remarks, and Meeting Overview



Jim Brett
PCPID Chair

Welcoming Remarks from Administration for Community Living



Alison Barkoff
Acting Administrator, ACL



Jill Jacobs
Commissioner, ACL

Summary of Public Comments Received



David Jones

Director, Office of Intellectual and
Developmental Disabilities



HCBS / Direct Support Professionals

HCBS / Direct Support Professionals

Workgroup Members

Co-Chairs:

- **Nicole Jorwic**, *Citizen Member*
- **Joe Macbeth**, *Citizen Member*
- **Tia Nelis**, *Citizen Member*

Members:

- **Kara Jones**, *Citizen Member*
- **Cathy Kanefsky**, *Citizen Member*
- **Hillary Dunn Stanisz**, *Citizen Member*
- **Wendy Strauss**, *Citizen Member*
- **Jodie Sumeracki**, *Ex Officio Member*
- **Liz Weintraub**, *Citizen Member*

HCBS / Direct Support Professionals

Issues Surfaced by Workgroup

- Low wages for DSP Workers;
- Limited technology solutions;
- Poor business acumen and workplace culture;
- Marketing and recruitment to expand the pool of workers;
- Explore and expand Self Direction Models;
- Need to create unique personal identity;
- Lack of professional standards; and
- Lack of career ladders and credentialing opportunities.

Workforce Challenges

Workforce issues such as recruitment, retention and training of direct support workers **have always plagued community services** to people with I/DD.

Unfortunately, there is **no surplus of people** willing to become direct support workers. This may be because the job itself is **not easy** or because the industry is challenged by **high turnover rates, low social value, lack of professional recognition, severe staffing shortages, lack of career ladders** and opportunities for direct support workers and **near poverty level wages**.

Workforce Conditions Deter Recruitment and Retention



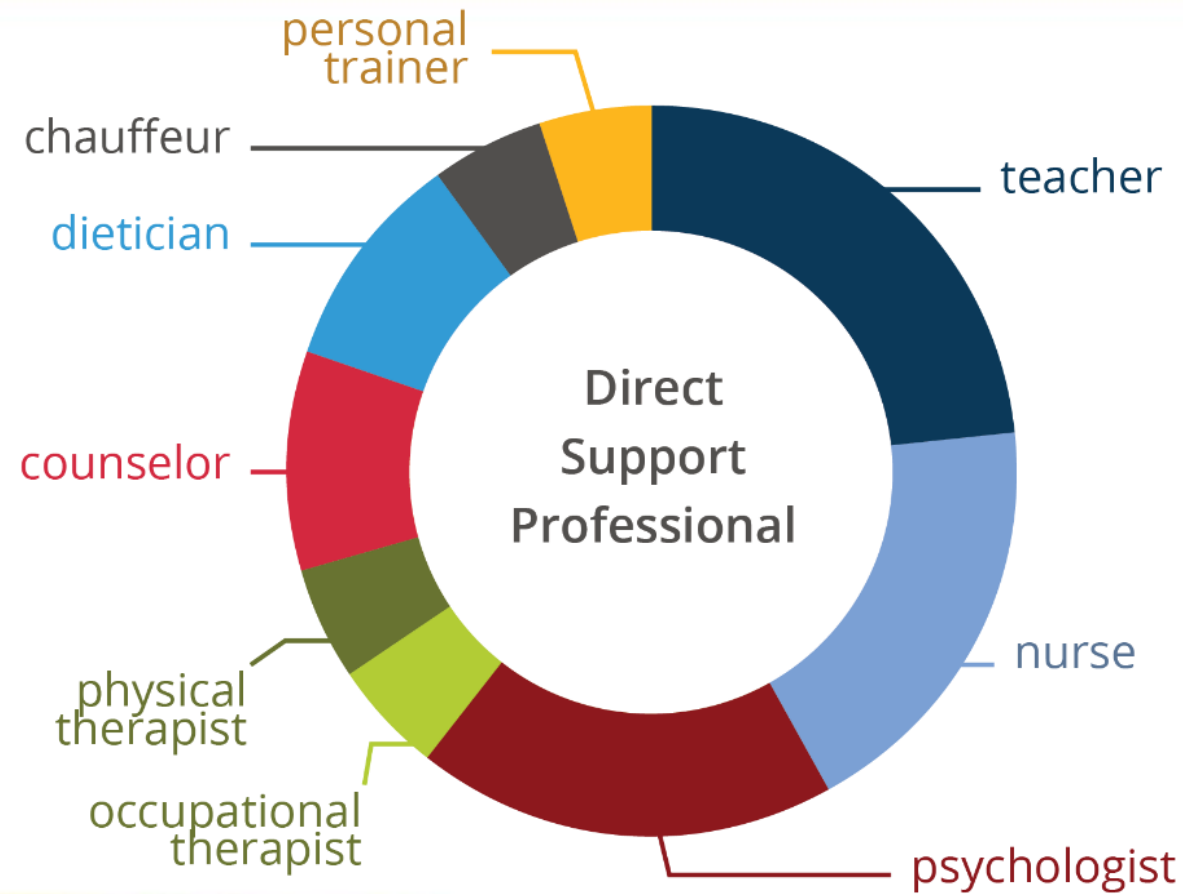
How Do We Define Quality in HCBS?

“It is defined at the **point of interaction** between the staff member and the individual with a developmental disability.”

*John F. Kennedy, Jr. (1995)
Chair, President’s Committee for
People with Intellectual Disabilities
& Founder, NADSP*



Direct Support: A Highly Skilled Profession



High Expectation Discrepancy

Specialized Knowledge

Support Healthy Relationships

Teach

Comply with Rules and Regulations

Understanding Ethical Responsibilities

Documentation

Support Choice & Mitigate Risk

Promote Health & Wellness

Culturally Competent

Understand & Respect Rights

Provide Complex Medical Supports

Problem Solving Skills and Judgement

Person-Centered Supports



The Emerging Roles of the Direct Support Workforce

Historically....

- **Primarily Seen as Caretaker**
- **Focus on Custodial Care**
- **Providing Companionship**
- **Providing Coverage**
- **Primarily Focused on Health & Safety Issues**
- **Entry-Level & Dead-End Job**

Now and in the Future....

- **Ambassador, Mentor & Coach**
- **Culturally Competent**
- **Close Interactions with Medical Professionals**
- **Supporting Informed Decisions – Assessing RISK**
- **Using Technology to Support Human Growth & Independence**

The Changing Expectations of the Direct Support Workforce

Historically....

- **Blindly Follow the Written Plan**
- **Filling shifts**
- **Rely on readily available supervision**
- **Community Outings**
- **System-Centered Identification**

Now and in the Future....

- **Creating meaningful plans *with* People they support**
- **Helping people build meaningful friendships & relationships**
- **A distinct focus on Inclusion – not "community outings"**
- **Advocating WITH – not FOR people with disabilities**
- **Presuming Competence and Focusing on Skills, rather than Needs**

Occupation

~~VS~~

Profession

Which is Direct Support?

Occupation is an activity undertaken by the person to earn his/her livelihood. It can be business, profession or employment that a person undertakes to make money.

Profession is an activity that requires specialized training, knowledge, qualification and skills. It implies membership of a professional body, and certificate of practice. The individuals who undertake a profession of rendering personalized services are called professionals, who are guided by a certain code of conduct, set up by the respective body.

A Common Job Title

~~Residence Counselor~~

~~Program Instructor~~

~~Community Bridge Builder~~

~~Disability Aide~~

~~Mental Hygiene Therapy Aide~~

~~Disability Support Counselor~~

~~Community Connector~~

~~Individual Support Specialist~~

Direct Support Professional

A diagram illustrating the consolidation of various job titles into a single common title. On the left, eight job titles are listed, each with a horizontal line through it, indicating they are being replaced. Two arrows originate from the top and bottom of this list and point towards the right, where the new, common job title 'Direct Support Professional' is written in a large, bold, black font.

A Common Definition

Direct support professionals (DSPs) assist people with intellectual and/or developmental disabilities in realizing their full potential and becoming valued and participating members of their communities. Their work is complex and goes well beyond caregiving, requiring skills including independent problem solving, decision making, behavioral assessment and prevention, medication administration, health and allied health treatment, teaching new skills, crisis prevention and intervention and more. The job duties of a DSP may resemble those of teachers, nurses, social workers, counselors, physical or occupational therapists, dietitians, chauffeurs, personal trainers, and others. Their work requires strong communication skills and the ability to build relationships with the people they support and their families. DSPs may work in family or individual homes, intermediate care facilities, residential group homes, community job sites, vocational and day programs, and other locations. Their work is determined by the unique needs and preferences of the individuals they support and they are held to high ethical and professional standards.

Guest Panel

- **BJ Stasio**, *New York*
- **Nguungwan (Victoria) Afa**, *Tennessee*

PCPID MEMBER DISCUSSION





BREAK

10 minutes



HCBS / Employment

HCBS / Employment Workgroup Members

Workgroup Members

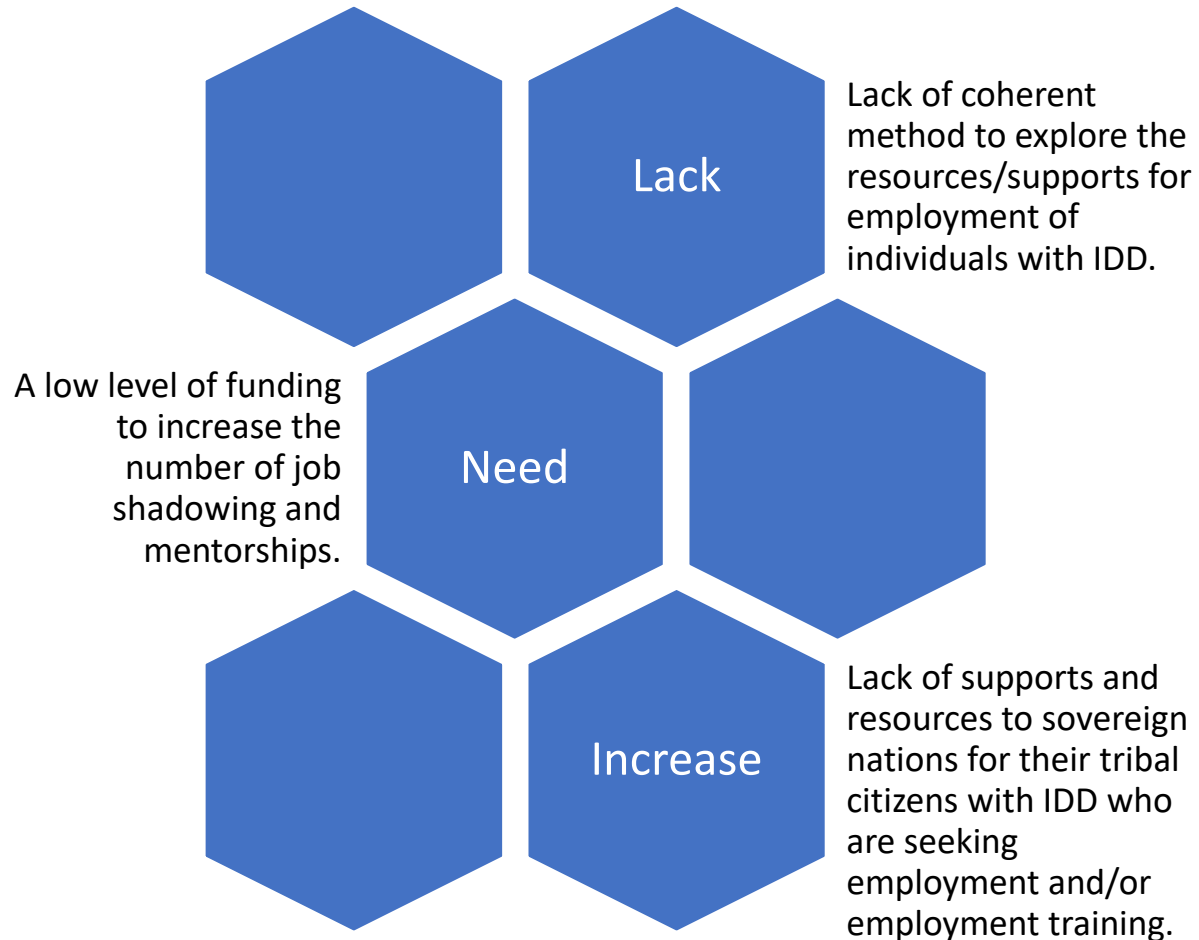
Co-Chairs:

- **Eva Bunnell**, *Citizen Member*
- **Gabriel Martinez**, *Citizen Member*

Members:

- **Alyse Bass**, *Ex Officio Member*
- **Cathy Kanefsky**, *Citizen Member*
- **Max Lapertosa**, *Ex Officio Member*
- **Brent Leonhard**, *Citizen Member*
- **Lucy Meyer**, *Citizen Member*
- **Katy Neas**, *Ex Officio Member*
- **Nick Perry**, *Citizen Member*

Issues Identified on Meaningful Employment



- As of May 2022, individuals with disabilities represented 9.4% of the federal workforce. We believe it would be a good practice to increase that number.
- Expiration of the Work Opportunity Tax Credit (WOTC) in 2025.
- Expenses incurred by employers for disability hiring despite mandated agencies, such as VR and Workforce Development, and the challenges associated with said agencies; and
- Low pay rate for Vocational Rehabilitation (VR) supported employment services.
- Many individuals with I/DD and other types of disabilities seek or secure employment through the businesses and companies owned by others. There are, however, few opportunities that can support individuals in becoming entrepreneurs and being self-employed successfully;

What percentage of people with IDD are employed?

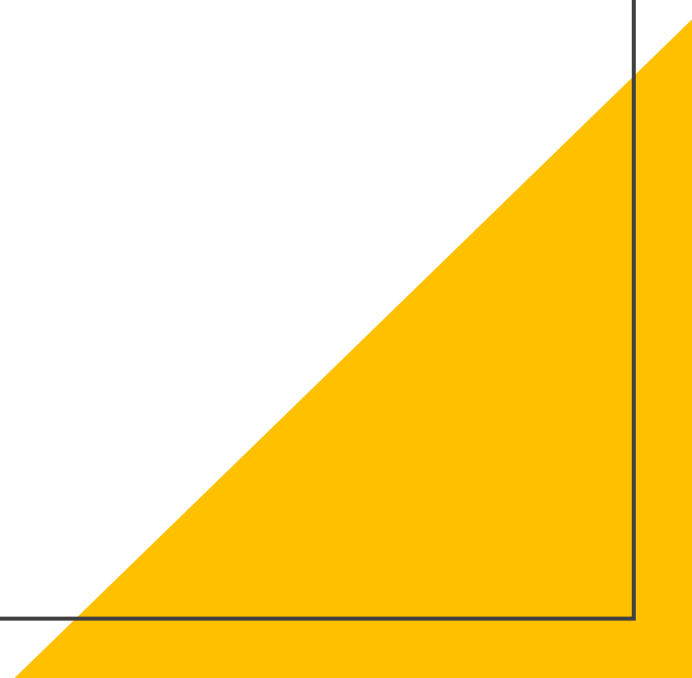
- ...less than one out of every two working age adults with IDD is in the labor force (i.e. currently employed or searching for work). Only 44% of adults with ID aged 21-64 are in the labor force.
- 28% of working age adults with ID have never held a job.

-National Snapshot of Adults w IDD in the Labor Force, Special Olympics

Are people with disabilities more likely to be self employed?

Overall, people with disabilities {all} are still less likely to be employed than their counterparts who don't have disabilities, and they are twice as likely to be employed part-time, the BLS report said. "However," they're also more likely to be self-employed.

-Fortune.com, Feb 24, 2023

A large yellow triangle is positioned in the bottom right corner of the slide, pointing towards the top right.

What do we know about self-employment of individuals with disabilities?

A larger share of workers with a disability were self-employed in 2022 than were those with no disability (9.5 percent versus 6.1 percent). In contrast, a smaller share of workers with a disability were private wage and salary workers (76.7 percent) than were those without a disability (80.5 percent).

-Bureau of Labor Statistics, 2022



LINKS TO MORE INFORMATION

Rhode Island – Rhode Island DD Center Business Series (You Tube Video)

https://www.youtube.com/watch?v=RvYh71pz9_Q

Tennessee - Direct Support Professionals Supporting Employment

<https://publications.ici.umn.edu/frontline-initiative/18-2/when-allan-feels-valued-it-makes-a-world-of-difference>

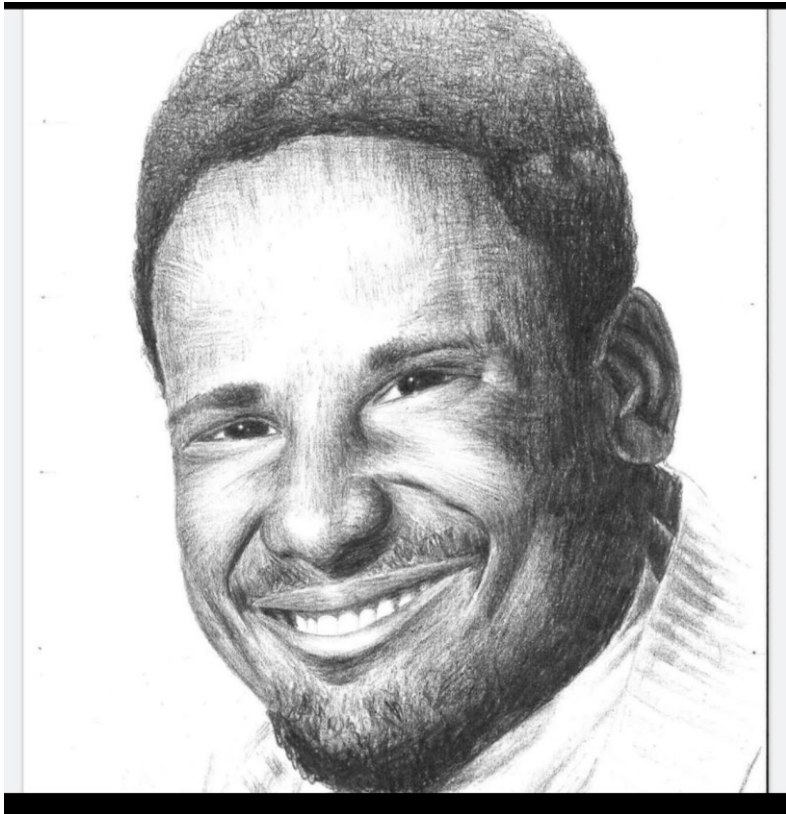
National Snapshot of Adults with Intellectual Disabilities in the Labor Force:

- [StateData.Info](#) – See the latest trends in state performance in work and participation for people with intellectual and developmental disabilities.
- [National Snapshot of Adults with Intellectual Disabilities in the Labor Force](#) – Research study commissioned by Special Olympics through Center for Social Development and Education at the University of Massachusetts Boston and administered by Gallup.

Guest Panel

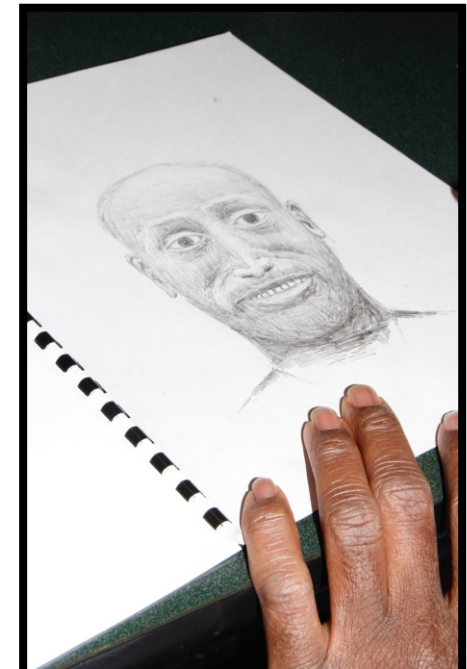
- **Alton Stuckey**, *Rhode Island*
- **Joshua Drywater**, *Arizona*

Alton Stuckey, RI Business Owner, “Alton Stuckey Portraits & Beyond”



How I Started My Business

- I was 14 years old and started to draw.
- In the 90's I was at a day program and started to draw there too.
- They were an agency that worked with people who wanted to learn art.
- Some staff were graduates of University Art Programs.
- They helped me to learn new things.



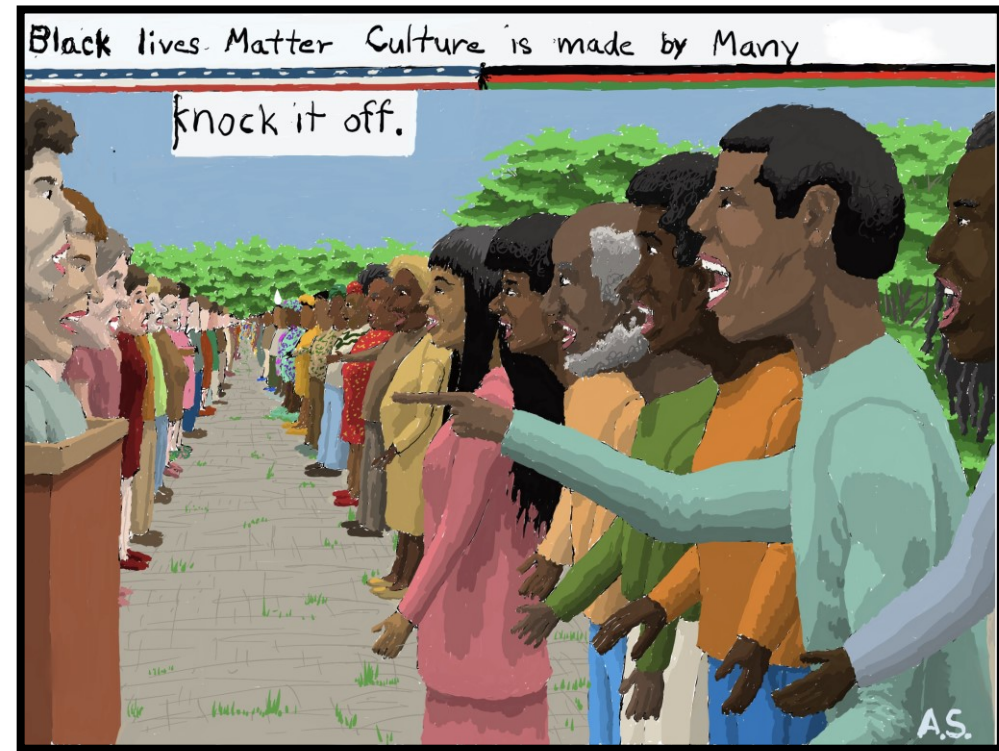
My First Steps To Own My Business

- I took abstract art Classes at RI School of Design.
- Then I started doing portraits.
- My agency thought I was creative and had talent.
- They would bring up images on the computer that I would draw.
- They helped me to promote my work.



About My Business

- I started my Business in 2019
- I create portraits of people, pets, or wedding couples from individual photos.
- I use watercolors, pencils, paint, charcoal.
- I also create paintings and abstracts of landscapes and seascapes.
- I create an annual calendar of my favorite works of art.



Why I Love Being a Business Owner

- Getting orders from people
- Making some money
- Meeting people and sharing my talents
- It makes me happy
- I'm proud of myself!



Where I Sell My Art

I sell my art products:

- Online through Instagram,
- Pop-up Art Shows,
- “Small Business Saturday SHOP RI”,
- My Church, and
- By word of mouth.



Other Support

- My family helped me with funding for supplies, materials, etc. that I needed.
- I took Business Classes on Self-Employment through the RI Developmental Disabilities Council (RIDDC).
- RIDDC gave me a grant for more supplies and materials for my business.
- I also use funding from self-directed supports from State DD for staff to help me with my business production, going to events, and tracking sales



MY Recommendations

1. Tell People they CAN DO IT and DON'T GIVE UP!
2. More self-employment programs top help people learn about HOW to start a business.
3. Funding from DD Medicaid Waiver to help people to buy necessary materials, supplies, small equipment for their business.
4. Funding from Vocational Rehabilitation to support business owners with disabilities.
5. Places in the community where people can go to use for production space to create their works of art or products.
6. Approval from Social Security to keep your SSI Check and earnings for 1-3 years to get your business really going.



THANK YOU!

You can contact me through
my Mom, Iraida Williams

Email:

Iraida28@hotmail.com

Phone:

401-465-2838



Instagram: [@Altonstuckeyart](https://www.instagram.com/Altonstuckeyart)



THE UNIVERSITY OF ARIZONA
COLLEGE OF MEDICINE TUCSON

Sonoran Center for
Excellence in Disabilities

Employment Landscape for Native Populations





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Sonoran Center for
Excellence in Disabilities

PRESENTATION AGENDA

- Introduction
- Current State of Employment
 - Issues
 - Gaps
 - Best Practices
- Questions



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Sonoran Center for
Excellence in Disabilities

Introduction



Expanding possibilities and enhancing independence through education, research and service



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Current State of Employment



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Issues/Barriers

- Transportation
- Technology
- Service Access Shortages
- Social Services



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Gaps

- Advocacy
- Outreach and Training
- Communication
- Opportunities



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Best Practices

- Culture-informed
- Community-based
- Family orientated
- Resiliency



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Considerations Moving Forward

- Building upon the Native Community Framework
- Tightening Communication at all levels
- Development of Integrated Resource Teams



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Sonoran Center for
Excellence in Disabilities



R. Joshua Drywater
Program Manager, Native Initiatives
Sonoran Center For Excellence in Disabilities
The University of Arizona
rjdrywater@arizona.edu

PCPID MEMBER DISCUSSION





BREAK

10 minutes



HCBS / Community Living

HCBS / Community Living

Workgroup Members

Co-Chairs:

- **Santa Perez**, *Citizen Member*
- **James Trout**, *Citizen Member*

Members:

- **Kelly Buckland**, *Ex Officio Member*
- **Max Lapertosa**, *Ex Officio Member*
- **James Meadours**, *Citizen Member*
- **Brian Parsons**, *Ex Officio Member*
- **Wendy Strauss**, *Citizen Member*
- **Jodie Sumeracki**, *Ex Officio Member*
- **Debra Tidwell-Peters**, *Ex Officio Member*
- **Jeanine Worden**, *Ex Officio Member*
- **Jordyn Zimmerman**, *Citizen Member*

HCBS / Community Living

Issues Surfaced by Workgroup

Assistive Technology

- Individuals with ID/DD need to learn Assistive Technology at an early age.

Disaster Preparedness

- Ensuring people with ID/DD have more knowledge about disaster preparedness; and
- Lack of understanding, knowledge, coordination surrounding durable accommodations.

Education

- Lack of services and support K-12 and during transition period.

HCBS / Community Living

Issues Surfaced by Workgroup

Housing

- Being independent on federal subsidy;
- Lack of affordable and accessible housing near transportation hubs;
- Towns created exclusively for people with ID/DD do not promote community inclusion;
- Not enough public affordable housing in desired areas;
- Lack of awareness and planning around housing opportunities for with disabilities / need to start transition planning early;
- Zoning restrictions limit the availability of housing options that could provide additional types of community living; and
- Individuals with disabilities face discrimination from landlords.

HCBS / Community Living

Issues Surfaced by Workgroup

Personal Safety

- Protection from physical and emotional abuse or exploitation in their home/place of residence and in any community setting; and
- Adults with Intellectual Disabilities are at high risk of getting sick when attending adult day care centers (e.g. pandemic).

Transportation

- Accessibility in urban and rural communities.

Guest Panel

- **Amanda Baker**, *Florida*
- **Bryan Russell**, *Florida*
- **Vance Taylor**, *California*
- **Kira Meskin Schiff**, *Illinois*

The Hurricane Michael Effect

Amanda's Apartment

October 6, 2018



October 10, 2018



Amanda's Street Hours After Storm

Disaster and Emergency Planning Resources



Disability Topics Page

https://disabilityrightsflorida.org/disability-topics/category/disaster_and_emergency_planning

Emergency Preparedness Resources

- Are You Prepared for an Emergency Brochure
- Special Needs Shelter Podcast
- Evacuate/Shelter-in-Place
- Shelters and Accessibility
- Pets and Service Animals
- Medication Access
- Links to Other Resources throughout the state.

Hurricane Resources & Information

Updated with information regarding most current disaster (Currently Hurricane Ian)

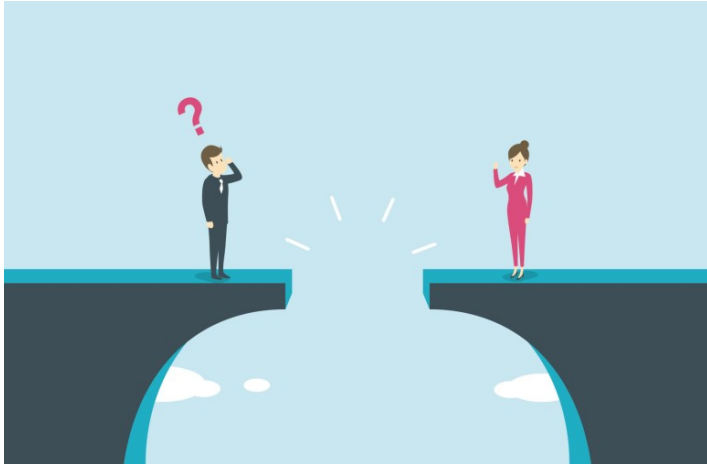
Please contact Disability Rights Florida at:

2473 Care Drive, Suite 200
Tallahassee, Florida 32308

800.342.0823 • TDD 800.346.4127

www.DisabilityRightsFlorida.org





Gaps and Barriers in Emergency Preparedness

Kira Meskin Schiff

- Vice Chairperson, Illinois Emergency Management Agency's Access and Functional Needs. Advisory Committee
- Community Reintegration Advocate, Progress Center for Independent Living
- Occupational Therapist
- Home Modification Specialist
- Certified ADA Coordinator
- Primary Co-leader of PPE for People With Disabilities Coalition

People with Disabilities Are Often Forgotten



- Emergency management agencies at the federal, state, and local level have legal and ethical obligations to meet the needs of people with disabilities
- People with disabilities are not effectively considered in emergency management services
- The COVID-19 pandemic brought to light a lot of problems in Illinois
- People who use and provide Home and Community Based Services were left out of emergency management services
- Emergency management agencies also need to prepare and plan ahead of time

Concerns With Illinois' Emergency Management



- Home and Community-Based Services are not a priority for Illinois
- There is little coordinated and systematic efforts between state agencies
- Direct Support Professionals and Personal Assistants are essential workers, but they are not viewed as important
- Centers for Independent Living and Illinois Council on Developmental Disabilities could be **more** effective with **more** education, guidelines, and support to provide emergency preparedness services
- Emergency Managers need to actually follow disability laws and policies

Poor Communication With the Public



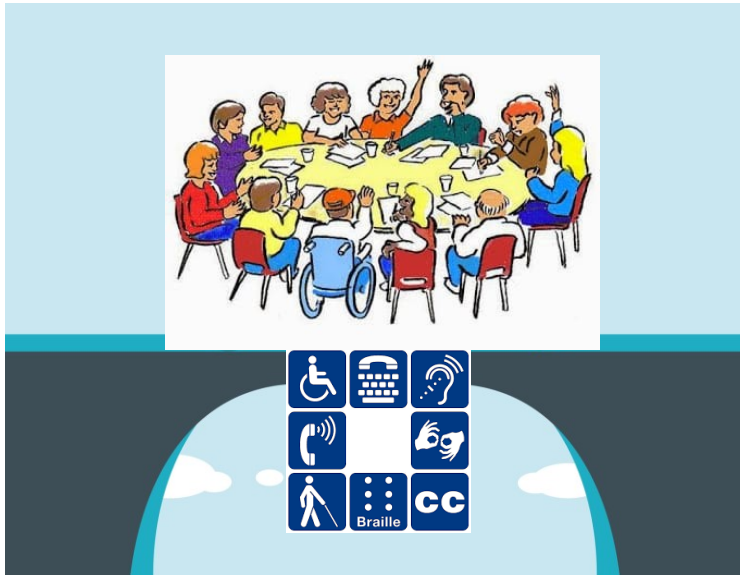
- We need communication that actually reaches us and is understood by us
- If we are not informed, we do not know what our rights are, our options for services, how to advocate and make complaints
- Access to technology, the internet, and information are huge barriers

Making Communication Truly Accessible And Effective



- Follow the Americans with Disabilities Act requirements on effective communication
- Use multiple types of communication at once
- This means sending mail **and** making phone calls **and** sending texts messages **and** emails **and** going to people's homes
- Use plain language Universal Design and easy read materials
- Consider formal and informal caregivers
- Share information more than one time

Including People With Disabilities



- Talks about equity often do not include disability
- "Nothing About Us, Without Us" means being in the room where it happens
- We need Access and Functional Needs Office, Staff, and Advisory Committees in every state
- We need to be included as leaders and subject matter experts
- Create contracts with Centers for Independent Living, State Council on Developmental Disabilities, The Arc, and other disability-led organizations
- Include us in data collection

Thank You To The People Who Helped Me



- Tia Nelis, President's Committee for People with Intellectual Disabilities
- Kimberly Mercer-Schleider, Illinois Council on Developmental Disabilities
- Krescene Beck, Illinois Self-Advocacy Alliance and Blue Tower Solutions
- Leanne Mull, Blue Tower Solutions
- Meg Traci, Rural Institute for Inclusive Communities, University of Montana
- Sadie Martinez, Colorado Division of Homeland Security and Emergency Management
- The Partnership for Inclusive Disaster Strategies

PCPID MEMBER DISCUSSION





BREAK

10 minutes



HCBS / Federal Support Programs



Home and Community-Based Services

Understanding the need to reform
key federal support programs.

The Financial Imperatives

The Moral Imperatives

HCBS / Federal Support Programs

Workgroup Members

Co-Chairs:

- **Shawn Aleong**, *Citizen Member*
- **Paul Aronsohn**, *Citizen Member*

Members:

- **Alyse Bass**, *Ex Officio Member*
- **Paul Boskind**, *Citizen Member*
- **Leola Brooks**, *Ex Officio Member*
- **Lisa Gray**, *Ex Officio Member*
- **Jodie Sumeracki**, *Ex Officio Member*



Home and Community-Based Services

“Home- and Community-Based Services (HCBS) are types of person-centered care delivered in the home and community.... HCBS are often designed to enable people to stay in their homes, rather than moving to a facility for care.

HCBS programs are often funded by state waivers. Waivers are part of a state's Medicaid program, but they provide a special group of services to a certain population. Waivers usually require medical and financial eligibility....”

-- from CMS.Gov

HCBS is a Medicaid program that helps make it possible for people with disabilities to live in the community.

Medicaid eligibility is therefore absolutely necessary.

Medicaid 2023	Single	Couple
Income	\$914 / month (many states)	\$1,371 / month (many states)
Assets	\$2,000 (many states)	\$3,000 (many states)

However, current Medicaid income and asset limits are too low, and married couples are penalized.

Supplemental Security Income eligibility is therefore often very important.

Supplemental Security Income (2023)	Single	Couple
Income	\$941 / month (national limit)	\$1,391 / month (national limit)
Asset	\$2,000 (national limit)	\$3,000 (national limit)

However, current SSI income and asset limits are too low, and married couples are penalized.

Other Federal Programs are often very important, too.



Medicare.gov

Medicaid.gov
Keeping America Healthy



However, other federal programs also pose challenges for people with disabilities wanting to live in the community.

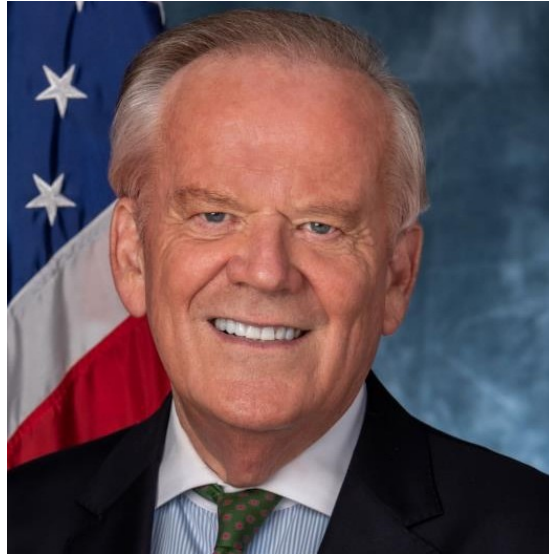
Guest Panel

– **Patrice Jetter**, *New Jersey*

PCPID MEMBER DISCUSSION



Closing Remarks / Next Steps



Jim Brett
PCPID Chair

THANK YOU