



# The Value of Independent Living and Self Direction

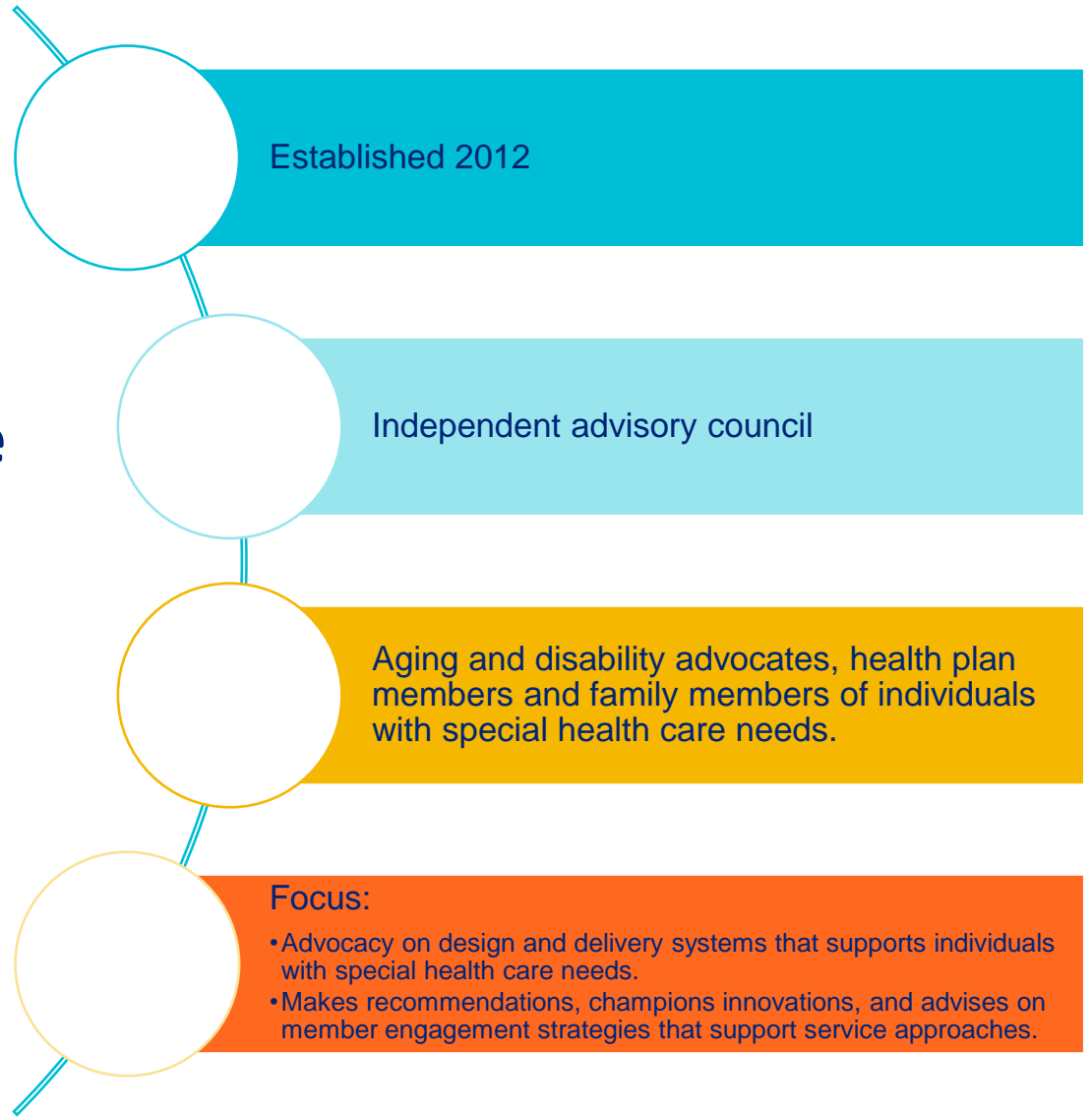
2021 HCBS Conference  
December 8, 2021

For Internal Review Only

United  
Healthcare®

# UnitedHealthcare Community & State

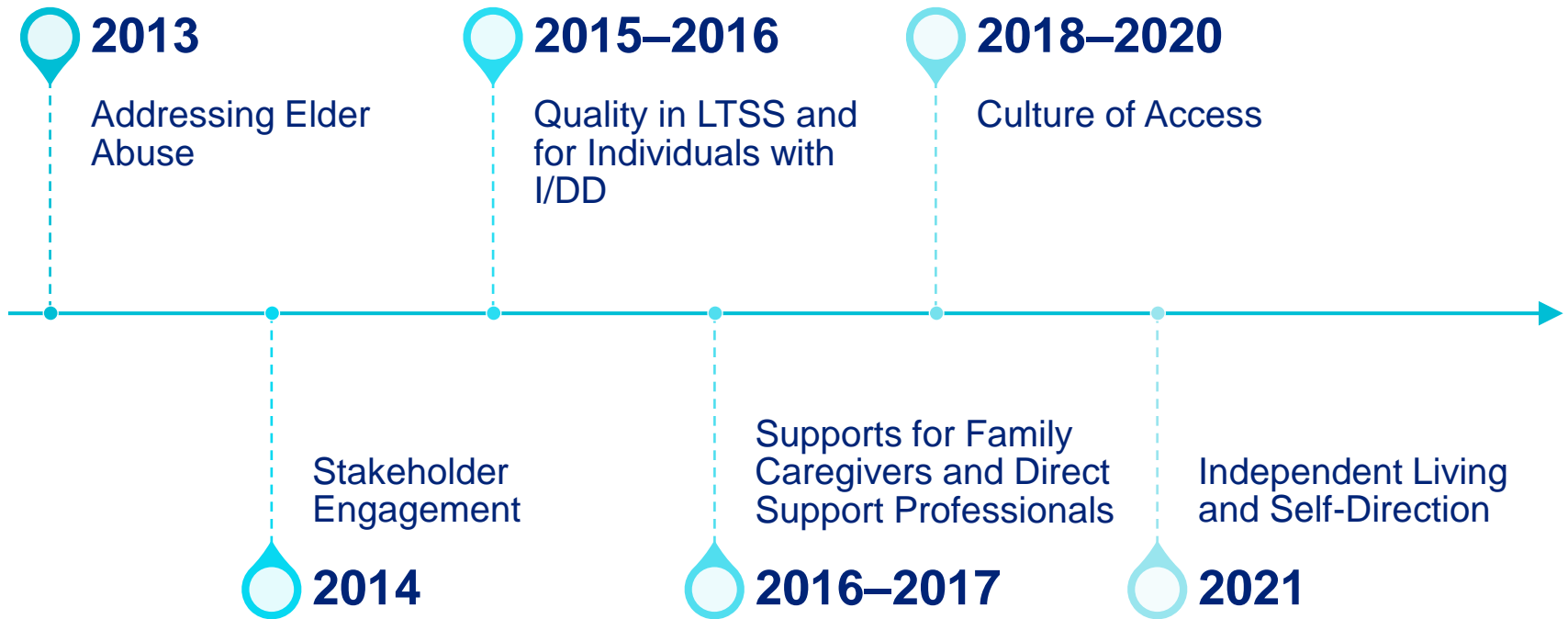
## National Advisory Board



# National Advisory Board Representation



# NAB Areas of Focus



# Independent Living & Self-Direction

To continue **to advance consumer-centered programs**, we must deepen our collective understanding of independent living and self-direction and **implement key program design changes to achieve a greater adoption.**



# Independent Living

**“If people with disabilities have a future, then everyone in our society will have a future.**

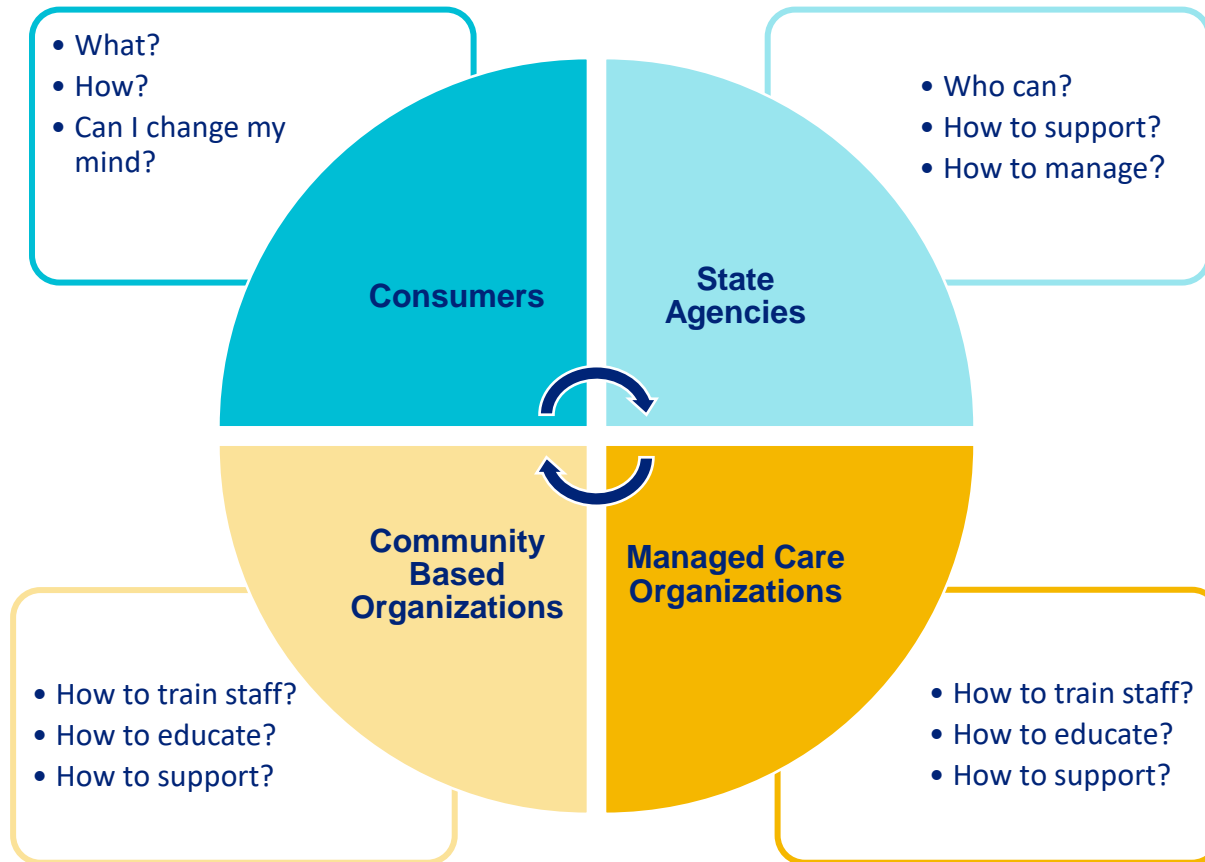
And when there's maximum danger, and when our programs are in the most jeopardy, there's also maximum opportunity. To make changes in them, to fight for what we know we need, to make them more responsible for the needs of our people to and let's take advantage of that. Let's figure out some alternatives, let's not just be naysayers.

And we're going to develop leadership, that has a fundamental difference and that is, it's inclusive . It believes in people, and in our strengths together.”

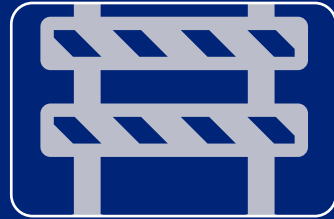
**-- Ed Roberts, 1981**



# Self-Direction

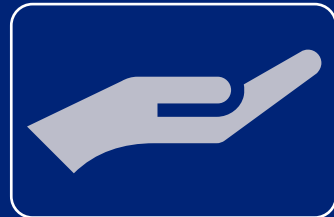


# Program Design Changes



## Remove Barriers

- Staff training
- Allow for all populations
- Expand Caregiver Options



## Strive for Equity

- Streamline application process
- Simplify tools to support Self-Direction



## Support Caregivers

- Training requirements
- Training programs





# Jennifer Kucera: The Consumer's Voice



# HCBS CONFERENCE

Home & Community-Based Services



- My hope is that you take some of the things that I tell you today and think about them when you are creating policies, procedures and programs that help your consumers live better lives.



# My Story

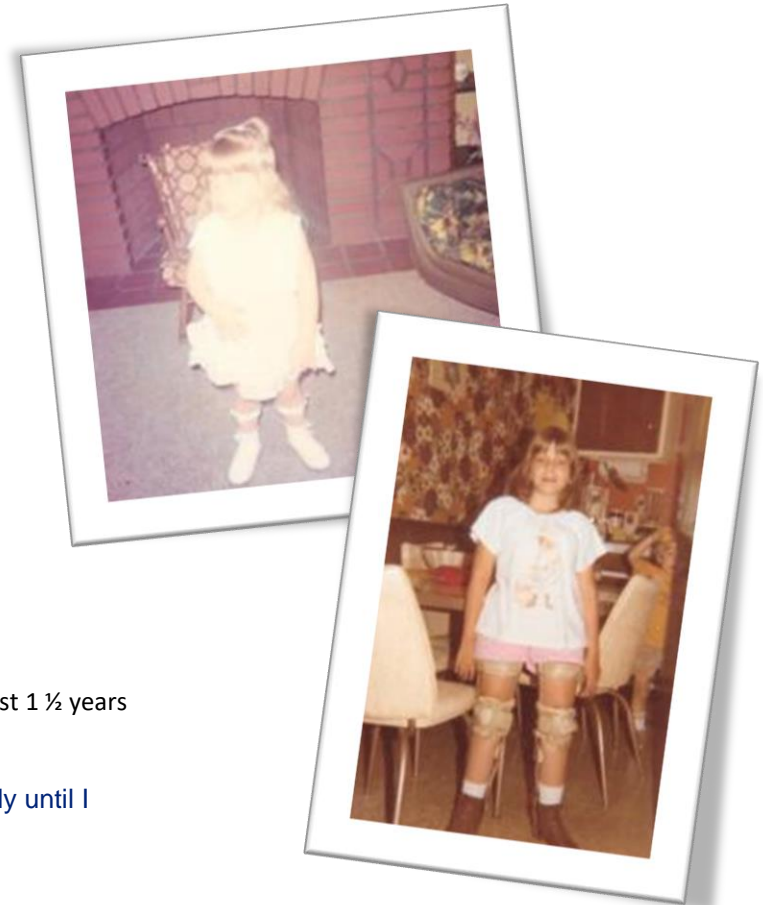
- ❖ Born with Spinal Muscular Atrophy, form of Muscular Dystrophy
- ❖ Scoliosis of spine – S shaped curve

I walked until around 3rd or 4th grade with leg braces

Eventually went to using a wheelchair full-time

Parents were told I wouldn't survive past 1 ½ years old

So I stopped seeing doctors regularly until I turned 30



# My Story

I've **never** let my disability stop me from achieving my goals and dreams.

I attended College and got my BA in Psychology and Mathematics

Began working as Math tutor at Cuyahoga Community College

Math Instructor at Lorain County Community College, Cuyahoga Community College & Baldwin Wallace University – approximately 20 years

Age 30, got my 1<sup>st</sup> adapted van

Age 30 I moved out of my mom's house and lived with a caregiver for 14 years

❖ My 1<sup>st</sup> attempt at self-directed care



# My Story



Everything was great for awhile but then due to improper care - ED visits 3x per month with hospital stays

No consistent health coverage for 40 years



2  
year

Bad van accident  
put me in a  
Nursing Home

Prior to NH, NO  
consistent  
Health  
Coverage

NH helped me  
get started with  
Medicaid and  
eventually UHC

# Independent Living



Money Follows the Person program



**2016**  
Moved into my own apartment



# Let's talk about Independent Living!

DRIVE FOR FREEDOM



Lifelong goal has always been living my life as independently as I possibly can

“Independent living regards individuals living with disabilities as the same as their non-disabled counterparts, enjoying all the same freedoms and civil rights”

We ALL just want to be who we are and to live a life worth living !

“The concept of **independent living** originated in the 1960s when the deinstitutionalization movement took hold”

“Independent living is often defined differently across groups and individuals and does not always mean living alone.”

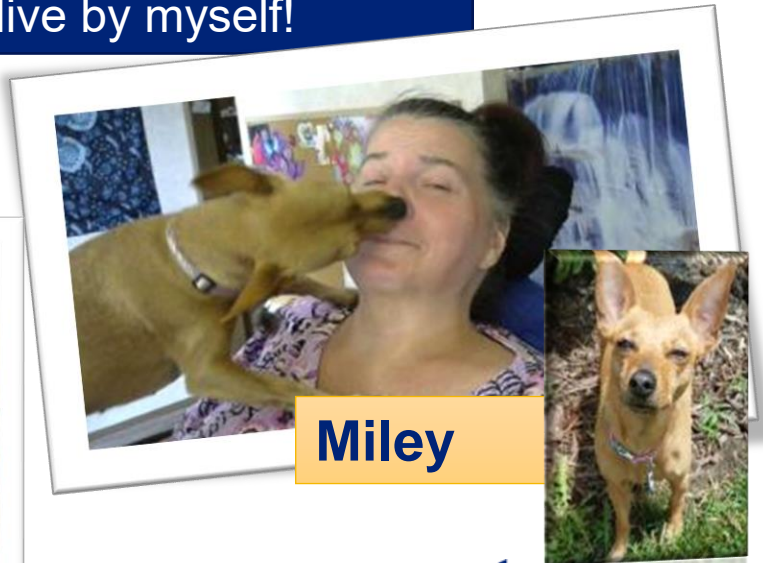
We **MUST** get people out of institutions !



# Independent Living

Currently only have use of my left arm from elbow to fingers!

But I've figured out a way to live by myself!



**Miley**





# Independent Living

Independent Living would not be possible without:

1. Assistive Technology
2. Medicaid
3. Reliable Caregivers



# Independent Living

## Assistive Technology

- ❖ Cellphone holder
- ❖ Beauty Salon tray & hose
- ❖ Faucet extension – Dad made
- ❖ Hoyer lift
- ❖ Door opener
- ❖ Pvc shower chair
- ❖ Smart speakers – part of backup plan (calamities)
- ❖ Alexa enabled devices, such as smart plugs, smart lightbulbs

- Home-made inventions
- Store bought
- 3D printers

High Tech

Low Tech



> help kids to wash easily  
> washing hand independently  
> Safe & Easy & Convenient

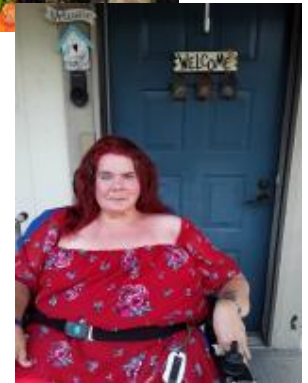
Faucet Extender: to help kids closer to faucet

# Challenges to Achieving Independent Living

- ❑ *Not enough HCBS Waiver slots*
- ❑ *Lack of Money Follows the Person availability & funding*
- ❑ *Lack of Accessible & Affordable Housing*
- ❑ *National shortages of caregivers as well as inadequate complex care needs training*
  - No knowledge on how to use **Hoyer lift system**
- ❑ *No portability in Waiver plans*
- ❑ *Low asset/income ceiling otherwise consumer loses benefits – i.e. cannot marry, can't get high paying job – stuck at poverty levels*
- ❑ *Reallocating the funds for services not being rendered (i.e. Nursing) to help subsidize other individualized lifestyle needs. (Patient - Centeredness)*



“Medicaid is unable to pay for room and board or rent for those living outside of institutional settings.”



# Independent Living

Independent Living is not possible without:

1. Assistive Technology
2. Reliable Caregivers
3. Medicaid

Split shift caregiving services

Help with all my ADLs

If carers don't show I don't get out of bed, don't eat and cannot use restroom

Caregivers can come from a variety of sources:

- ❖ Agency
- ❖ Self-Direction
- ❖ Family & Friends

# Self-Direction – general knowledge

- People with complex care needs **should** utilize self-direction
  - Cannot just send “anyone”
  - Don’t know person’s care needs
  - Gets frustrating and exhausting training new carers
  - Also frustrating and exhausting to carer
    - cause high absences & turnover rates



# Challenges to Engage in Self-Direction

- Lack of awareness or understanding of the Self-Direction Program on both ends (i.e. consumer & case manager)
  - State of Ohio Medicaid provider website is a mess!
- Provider database is completely outdated (i.e. phone numbers disconnected, no longer a carer (not care-taking))
- It is too difficult to navigate, Not user friendly



## Challenges to Engage in Self-Direction Cont.

- ▶ Must be mentally astute to navigate the hiring process and managing of carers (employer-employee dynamic)
- ▶ The breakdown of the Self-Direction program in instances when care needs drastically change
  - ▶ Mental/physical acuity - newly acquired disability
  - ▶ Huge learning curve for those with newly diagnosed disabilities (from no disability to being disabled)
  - ▶ Defaulting consumer back into the agency model
  - ▶ Attempting independent living for the first time, the fear of new challenges
    - ▶ Was easier to have church help pay for family/friend until was able to navigate the system

# Benefits of Self-Direction

- ▶ Seems that carers that are hired directly by consumers stay longer (one current caregiver with me for 6 years)
- ▶ Because of longevity of a carer they are more in-tune with the consumer's needs
- ▶ Folks with complex care needs and high amount of caregiving hours should have a team of 4-5 carers
- ▶ Consumer has more control of their services





# Independent Living



Independent Living is not possible without:

1. Assistive Technology
2. Reliable Caregivers
3. Medicaid

# Medicaid and Me

But  
NONE  
of this would be possible  
without the assistance of  
Medicaid!!

# Medicaid and Me



## Caregivers and Nursing Services

- Split shift, 365 days a year
- Help with all ADLs
  - Bathroom assistance
  - In/out of bed
  - Meal prep
  - Housekeeping

My Care Ohio Waiver – UHC,  
Medicaid, Medicare

## Prescriptions

- Prefer natural remedies
- Medicines

## Transportation Case Management

## Doctor Visits

- In person
- Tele-visits

## Durable Medical Equipment

- Power wheelchair with tilt, recline and raise features
- Hoyer lift
- Shower chair

**NO ED visits or hospital stays in 4 years !**

- ✓ Medicaid coverage
- ✓ Personal desire to stay well
- ✓ Caregiving and nursing team
- ✓ Seeing same Doctor regularly
- ✓ Case management team at UHC



**HCBS**  
**CONFERENCE**  
Home & Community-Based Services



# My Life in 2021



**Jo**

- ❖ Currently teaching Algebra to 9<sup>th</sup> graders



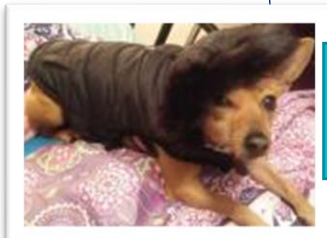
**Creating my Blog**

- ❖ Drivetowardfreedom.com

**Happy**

**Advocacy**

- ❖ UHC's NAB since 2019
- ❖ Metro Health's Patient Advisory Board
- ❖ MDA National Ambassador



- City council meetings
- Movies
- Restaurants

**Involved within the Community**

**Creating my Artwork**



## In Summary. . .

I have not discussed this stuff today because its my job or employment.

I talk about this because this stuff IS my life.

And if you all don't do your job then I don't get to have my life!



Contact information:

[Jenniferkucera134@gmail.com](mailto:Jenniferkucera134@gmail.com)

Questions?

