

The Research and Training Center on Promoting Interventions for Community Living

## **A Community Living Summit**

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### >> SLIDE 2: <u>Thank You</u> to our Scientist-Consumer Advisory Panel (SCAP) Members:

- Brian Abery
- Fabricio Balcazar
- Ron Garcia
- Catherine Graham
- David Keer

- Sierra Royster
- Phil Rumrill
- Tom Seekins
- Jack Stratton
- Ranita Wilks

# >> SLIDE 3: Community Living and Participation (CLP)

- Social connections play an important role in our overall well-being and quality of life
- Lack of these connections is associated with negative physical and mental health outcomes
- CILs play a critical role in supporting CLP for people with disabilities
- Research shows that people with disabilities who have more usable homes (e.g., in their bathrooms) are more likely to participate in the community
- Research shows that self-determination skills such as choice making, selfadvocacy, and self-management are positively associated with better community participation outcomes

#### >> SLIDE 4: What is PICL?

- The PICL project tested two CLP programs at six CILs across the country
- The "PICL program" consists of two consumer-directed programs designed for people with mobility disabilities:
  - The Home Usability Program
    - Goal-setting program to make a person's home more usable
  - Out and About
    - Goal-setting program related to community participation
- Overall goal:
  - To increase the community participation of people with mobility disabilities

#### >> SLIDE 5: Agenda for today

This forum will provide information about the programs, how Centers can use them, and important resources that are available.

- 1) Home Usability Program Lillie Greiman
- 2) Out and About Program Kelsey Goddard
- 3) National Community Living Resource Center Ryan Henley
- 4) The accessABILITY Experience Tammy Themel, Keshia Walker, & Susan Ferguson
- 5) Consumer Case Studies Randi Gray & Lyndsie Koon

>> SLIDE 6

## Home Usability to Support Community Living

Results and Next Steps from the PICL project

#### "It's life changing!"

-Consumer participant



### >> SLIDE 7: The Home Usability Program

- Usability vs. Accessibility
- Low-cost modifications, assistive technology, supports
  - \$350 per consumer
- Consumer driven
- Our research question: Does participation in a consumer directed home usability intervention increase community participation for consumers with mobility disabilities?
- Outcome data collected:
  - Community participation-trips and activities in the community
  - Levels of pain and exertion
  - Health

#### >> SLIDE 8: HUP Methods & Implementation

- Program content developed with a team of 5 CIL specialists from 5 different centers as part of pervious funding
- Consumers work closely with CIL staff to work through intervention online or with printed manuals
- Consumers complete a home usability plan throughout the process
  - Home usability quiz
  - Home usability self assessment-AARP Home Fit Guide
  - Resources (social and financial)
  - Included a home visit by CIL staff when feasible
- Results presented here from phase one in 2017-2019
- 195 consumers participated in a random control trial across two CILs
  - 81 completed the Home Usability Program

#### www.useablehome.com



About The Home Usability Program

Home Usability: Facilitator's guide Resources

Welcome!

Hello and welcome to the Home Usability Program. During this program, you can learn about home usability and the role it can play in independent living. You also can explore how to make your home more usable for you. In this program you will:

- 1. Learn about Independent Living, Self-Advocacy and Home Usability
- 2. Take a brief home assessment to identify possible home usability problems
- 3. Set a home usability goal to address possible problems and improve the usability of
- your home
- 4. Identify personal and community resources that can help you with your goal
- 5. Create a step by step work plan to help you achieve your goal

#### >> SLIDE 10: Home Usability Projects

- Bathing and grooming: Grab bars, shower chairs, non-slip mats
- **Cleaning**: Robot vacuums, long handled dusters, storage
- **Mobility**: Mobility devices such as walkers and canes
- General safety: Fire extinguishers, medical alert device
- Entrancing: Hand railings, video doorbells, threshold ramps

- **Cooking:** Adaptive cooking equipment
- Sleeping: New mattress
- Moving: Moved to a more accessible space
- **Dressing**: Assistive equipment
- Furniture: lift recliners, accessible desk
- Assistive equipment: Reacher tool

#### >> SLIDE 11: Results

- Consumer directed home usability changes positively impacted participation in social and recreational activities
- Program participants reported a 39.5% (p < .05) increase in social and recreational activities immediately following the intervention relative to the control group after controlling for health status and month
- Bathroom, safety and sleeping changes seem to have the greatest impact

#### >> SLIDE 12: Home Usability Program Quotes

- "[The Home Usability Program] kind of gave me a sense of if I were to do even more accessibility modifications to my home, kind of the process, kind of what I would need to think about and go through, prior to making that happen. So, making sure I have the money set aside, obviously, but also contacting people, getting different estimates, and things like that."
- "I learned how to better ask some questions. I also learned that there are resources available that you might not initially think of."

#### >> SLIDE 13: Success Strategies

- Community relationships and local partnerships
  - Furniture stores and durable medical equipment providers
  - Hardware stores, contractors/handymen
    - Habitat ReStores, Home Depot foundation grants
  - National/local nonprofit organizations
  - Thrift/resale stores (vouchers and discounts)
  - City governments
- Amazon wish lists and donation drives
- AT loan closets and AT loan/grant programs (State AT programs)
- Data communication and program marketing

#### >> SLIDE 14

# Questions?

>> SLIDE 15

#### The "Out and About" Program Life Expands in the Community

Results and Next Steps from the PICL project



#### >> SLIDE 16: The "Out and About" Program

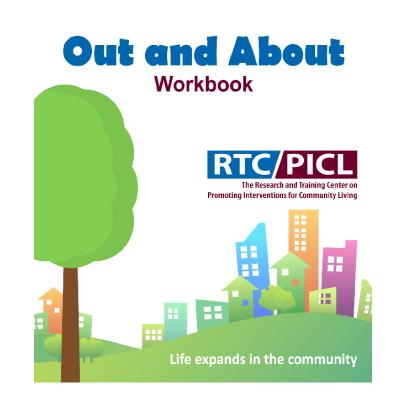
- Consumer-driven goal-setting program to increase community participation
- Learn what consumers want to do in the community
- Empower consumers to set goals and achieve them
- Facilitate consumers in breaking down barriers to get out and about
- Our research question: Does participation in a consumer-directed community participation intervention increase community participation for consumers with mobility disability?

#### https://outandabout.ku.edu



### >> SLIDE 18: Out and About (OAA) Steps

- Meeting 1
  - Choosing a Goal
  - Identifying Resources
- Meeting 2
  - Setting a SMART Goal
  - SMART Goal Tracking
- Weekly Check-In
  - Tracking Weekly Progress
- Final Meeting
  - Reviewing and Celebrating Progress



#### >> SLIDE 19: Out and About

		Advocacy	
Goal Area	OAA Goal		
Getting healthy	Going to the gym and identifying supports to join them	Home Living	
		Information Seeking	
Transportation	Using the paratransit system for the first time	Relationships	
		Getting and Staying Healthy	
		Navigating the Community	

#### >> SLIDE 20: Out and About Projects

- Attending a neurodiverse group
- Professional house cleaning
- Reliable transportation
- Going to church online
- Getting a service animal
- Socializing / meeting other people
- Using social media to stay in touch
- Learning to use a sewing machine
- Getting a laptop
- Engaging in social media

- Decorating for holidays
- Medication delivery system
- Food delivery systems
- Trivia night
- Going out in the community
- Fishing trips
- Exercise equipment
- Art class
- Typing to decrease fatigue
- Volunteer opportunities

#### >> SLIDE 21: PICL During the Pandemic

- Implications of the coronavirus pandemic on PICL:
  - Measures of physical participation in the community not as meaningful
  - People electing not to physically participate in their community
  - Community participation as a "luxury"
    - More people in emergency crises during the pandemic
    - Increased attention to meet basic needs
- Solutions:
  - Increased interviews to assess effects of PICL program on consumer's lives
  - Pivot to "community participation from home"
  - Learning from CIL staff about the needs of their consumers

#### >> SLIDE 22: Out and About Quotes

- "So, I think definitely the best thing was just kind of the connection with other people. I feel like it really has for me, at least increased a little bit during this COVID-19 pandemic... we all want to make sure that we stay connected because it can get very lonely when you're either by yourself or with the same group of people constantly."
- "[I learned] new information, learning about organizations that I didn't know were there. Kind of prompting me to actually do a little research of my own. Because otherwise I wouldn't have thought about looking up anything about food assistance or mobile meals or anything like that. So, it was good, excellent for information, because someday I may need it."

#### >> SLIDE 23

# Questions?

>> SLIDE 24

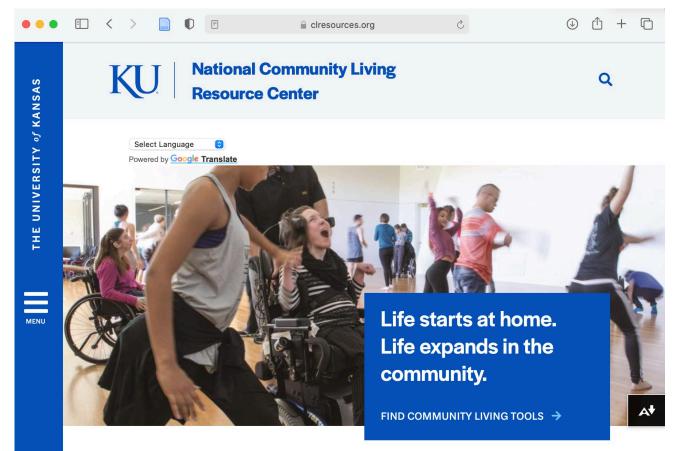
## National Community Living Resource Center

August 17, 2022

**Ryan Henley** 

# >> SLIDE 25: National Community Living Resource Center (NCLRC)

- What is the NCLRC?
  - A database of interventions of proven value to researchers, consumers, CILs, and others who promote community living for people with disabilities
  - <u>https://clresources.org</u>



#### >> SLIDE 26: Curated Resources

- We selected some of the best available resources that align with our review of the research on improving community living for people with disabilities.
- For each resource we tell you:
  - What the resource is
  - Why we chose to include it
  - Who benefits from it
  - How it can be used
- We also provide a link to the resource or a site where you can access the resource in full.

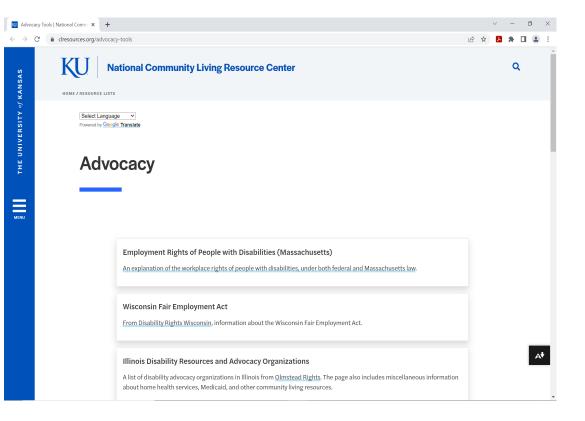
### >> SLIDE 27: Resource Lists

- <u>Advocacy</u>
- <u>Community Living Skills</u>
- Daily Living
- Disaster Preparedness
- Employment
- Financial
- <u>Health</u>

- Housing
- Legal
- Personal Care Attendants
- Service Animals
- Transition
- Transportation

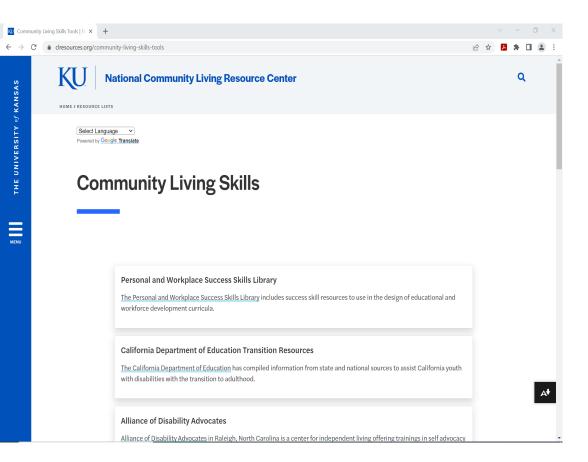
# >> SLIDE 28: Advocacy Resources https://clresources.org/advocacy-tools

- State Protection and Advocacy Systems created by the Administration for Community Living (ACL)
- Self Advocacy Guides created by Disability Rights of Pennsylvania
- Advocacy Skill Building Toolkit created by the University of Montana
- For more advocacy resources, visit our website!



# >> SLIDE 29: Community Living Skills Resources <a href="https://clresources.org/community-living-skills-tools">https://clresources.org/community-living-skills-tools</a>

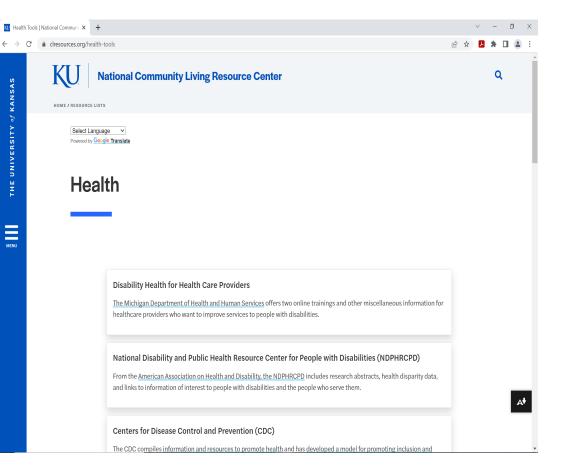
- Planning for Community Living created by the National Parent Center on Transition and Employment
- Administration for Community Living Program Areas created by the Administration for Community Living (ACL)
- Healthy Community Living site created by the Healthy Community Living (HCL) program
- For more community living skills resources, visit our website!



### >> SLIDE 30: Health Resources

https://clresources.org/health-tools

- National Disability and Public Health Resource Center for People with Disabilities (NDPHRCPD) created by the American Association on Health and Disability
- Rehabilitation and Choosing a Facility created by the Christopher Reeve Foundation
- Improving Access to Health Care for People with Disabilities created by the Disability Rights and Educational Defense Fund
- For more health resources, visit our website!



### >> SLIDE 31: Resource Lists

- <u>Advocacy</u>
- <u>Community Living Skills</u>
- Daily Living
- Disaster Preparedness
- Employment
- Financial
- <u>Health</u>

- Housing
- Legal
- Personal Care Attendants
- Service Animals
- Transition
- Transportation

#### >> SLIDE 32: Find Resources

- A search tool is available on our website under "Find Resources"
- Can filter by specific keywords and resource type

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THE UNIVERSITY of KANSAS	Find Resources	
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#### >> SLIDE 33

# Questions?

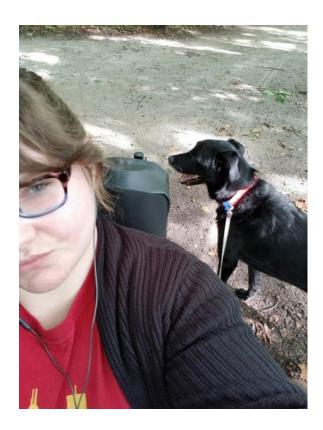
>> SLIDE 34

## PICL at accessABILITY



(317) 926-1660 • abilityindiana.org • info@abilityindiana.org

## >> SLIDE 35: Working with Consumers









## >> SLIDE 36: Working with Consumers

- accessABILITY and PICL procedures
- Autonomy and motivation

"[My CIL staff] is an angel. You don't meet too many people like that, with authentic empathy for people."





### >> SLIDE 37: Identifying Funding



- CARES Act Funding
- Partnerships with handy people
- Launching fundraising
- Covering an insurance deductible



#### >> SLIDE 38: Barriers

- Mid or high-risk outreach
- Project budgets
- COVID challenges
- Access to technology
- Basic needs





### >> SLIDE 39: **Testimonials**

"Thank God they got organizations like you guys. Like, there's not too much out there for people with disabilities, you know? And either you've gotta have a will of iron to see through it all, or you know, get a little help up from organizations."

"With the Home Usability Program, I felt like... I was going to feel better. I felt more optimistic about my health. I felt like it was making a difference."

"I learned that I could do more than I thought I could do."

"I learned how to better ask some questions."



### >> SLIDE 40: The Future

- Home Modification Committee
- Fundraising
- Continuing to build
   partnerships
- Seeing this as a barrier buster





#### >> SLIDE 41

## **Questions?**



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>> SLIDE 42

## HUP & OAA Case Studies

Randi Gray & Lyndsie Koon

#### >> SLIDE 43: Common HUP Goals

- Consumers had choice and control over Home Usability Program (HUP) goals
- Common HUP goals included:
  - Recliner chairs with lifts
  - Ring Doorbells compatible with Amazon Echo (Alexa)





# >> SLIDE 44: Recliner Chairs with Lifts, Heat, and/or Massage

- Most common home usability goal
- Why did consumers choose to get a recliner?
  - Need for furniture: "I had left all my furniture due to going through a bad relationship, and I had to start all over."
  - Pain (need for heat/massage): "I have scoliosis of the spine, and this recliner you could use to massage your back, and they had several regions that could be massaged. One was the lower back, and that's what was killing me."
  - Lack of mobility (need for lift): "My furniture is all low. And when my Sciatica would kick in, it was just like I'm stuck. Especially if nobody was here. I'm stuck. I couldn't get around."

#### >> SLIDE 45: Effects of Recliner Chairs

- Increased Dignity: "Before, with me not being able to get up, I wet my pants one time because I couldn't get up. But this chair, as I'm coming up, would give me that extra lift to get me moving."
- Decreased Pain: "I'm taking less of my medication now that I have the chair. Because my back would be inflamed, but the heat keeps it not inflamed. So yeah, I'm taking less medication, less pain pills."
- Increased Independence: "I can do my walks. I go to the mailbox now. Before I had my recliner, I just hoped I could get to the bathroom because I would be so inflamed. My back always hurt, 24/7. But now I have my heat."
- Increased Participation: "After I come home and I'm in the chair for 20 minutes, I can go back out into my community and do something more. Where before, I would have to come home and lay down, and try to get my body to stop aching. So yeah, it does help me to get out there."

#### >> SLIDE 46: Ring Doorbells with Video

- Why did consumers choose to get a Ring Doorbell with Video?
  - Safety concerns: "There is increased crime rate in the metropolitan area where I live, and I feel a bit safer because the area is being videotaped."
  - Home security concerns: "Whenever I'm out with my friends or my family, I want make sure that my home base is still protected whenever I leave."
  - Mobility concerns: "I love having the option for the like the ring doorbell thing that I got through the program because I don't have like even at the house, it was a long run to the front door and I'm upstairs whereas if somebody rings the doorbell you know I can just talk to them through my phone and I don't have to go there and I don't have to go downstairs."

#### >> SLIDE 47: Effects of Ring Doorbells

- Increased Sense of Safety: "I feel safer knowing maybe camera will catch next person who runs into my gate with their vehicle."
- Increased Sense of Home Security: "I still do the same things, in fact, I do it a lot more comfortably. It's given me a lot more time to be more in tune with my surroundings, and with the community whenever I do interact with people."
- Decreased Exertion: "With the doorbell, I don't have to be face-to-face coming to the door. It could be communication through the camera. It could be, 'Oh, yeah, I see you with the package. Just leave it there. Yeah, I'm getting my son to come get it.' And so that it means I don't have to use the energy to go to the door and open it to find out who's on the other side of it. And I can make decisions about when I need to go to the door. Like how quick to get there."

#### >> SLIDE 48: If Money Were No Object

- Need for one-story home and increased space for maneuverability: "I would level the whole thing. I'd burn it down to the ground, remodel the whole thing, make it bigger. Make it wider. Make the bedrooms a little bit bigger. I'd make everything bigger. I would not have [narrow] doors. I would have all 36 in."
- Need for increased space for assistive technology & durable medical equipment: "I want a two-bedroom. I need a two-bedroom because I have [assistive technology]. I have a lot of equipment. I have a lot of oxygen tanks and stuff all over, and I don't have enough room."
- Need to address risk of fall/injury: "I want a new refrigerator. My refrigerator is horrible. I make it work, but getting my hands and knees to get something out of the fridge is not ideal for me. I've made it work for almost eight years."
- Need to address basic needs: "I'm in an attic space, so, I would probably put a dedicated AC/heating unit up there."

#### >> SLIDE 49: Common OAA Goals

- Consumers had choice and control over Out and About (OAA) goals
- Common HUP goals included:
  - Accessing and learning to use technology
  - Exercising





# >> SLIDE 50: Setting Goals to Access and Learn to Use Technology

- Why did consumers choose a goal to access and learn to use technology?
  - Lack of access to information: "I guess I was just like a caveman. I didn't know what was happening in the world."
  - Lack of delivery options: "[Grocery shopping] took me forever. I get lost easy... I used to walk the supermarket without a mask to pick up my stuff probably three times a week."
  - Isolation: "With COVID, when I was restricted to the house, I didn't have work to see people, and I was not allowed out of the house. So, it was a nightmare for an entire year."
  - Lack of community participation: "I used to go to the movies at least once a month, before COVID. I haven't been to the movies to this day once COVID started. So that would be a nice thing to get to bump into people."

#### >> SLIDE 51: Effects of Using Technology

- Increased Access to Information: "It enables me to do research and look up things when I can't get to the library. It just makes it easier for me to do things that I can't normally get to."
- Increased Delivery Options: "The computer changed the way that I can order stuff [online] like my groceries."
- Increased Connection to Friends/Family: "Since the pandemic, the computer has been a big help because I can do a Zoom call like I did for my sister's birthday. That helped a lot. We did a Zoom call. Everybody was at their house. And all of us wished my sister happy birthday through a Zoom call. She was shocked."
- **Community Participation from Home:** "My church offers virtual, so I learned how to go virtually to be able to keep up with the church service."

#### >> SLIDE 52: Setting Goals to Exercise

- Why did consumers choose a goal to exercise?
  - Weight loss: "And it was my fault for not getting out to walk at least the six blocks to the park and six blocks back so that I add more steps so that I level off my weight. Right now, I'm fighting the weight. I'm on a diet, low calorie diet so that I'm able to stabilize my weight, but I need to lose more weight."
  - Mobility concerns: "The week before COVID started shutting everything down, I unexpectedly developed severe arthritis in my right knee, which is my good side. So, my ability to support my own weight to transfer into a driver's seat and to drive with that leg changes by day."

#### >> SLIDE 53: Effects of Exercising

- Increased Mobility: "It's all about keeping keeping my body in shape and being able to maneuver in and out of my apartment, in and out of my wheelchair. Being able to move from my wheelchair to a seat with no issues. I feel the more the more I work out, the less strain that I have to deal with."
- Increased Community Participation: "From walking and doing my route, I was like, well, if I can do the mile this way, I can probably just keep going and I can get to this Publix, or up to this Kroger. Or I can walk to the Trader Joe's to grab a few things. Kind of exploring the neighborhood a little more and finding some different areas to hang around in. I found a couple of little parks I've never seen before, and I've lived in that area for a very long time. I was like, oh look, a little park, there's a pond, let me hang out there for a bit. So, it was good in that respect to explore the community and kind of grow some of the routes that I would memorize and take."

#### >> SLIDE 54: PICL Takeaways

- "The best thing to come out of [the PICL program] is just me finding a sense of confidence and well-being. Knowing that you can make a change, it doesn't take long. I mean, the saying goes, 'It takes 21 days to form a habit.' And I'm happy that I made a habit from being a part of this program."
- "[I have] more self-esteem. The program just gives you a little bit of confidence and makes sure you feel better about yourself and don't focus so much on the disability."
- "I didn't really think people really gave much of a damn with people with impairments like that. That deeply, of course. So, I really learned that there are some very genuinely authentic people out there that really do. I really enjoyed building the bond that I had with [my CIL staff] over these past few months, so I really do appreciate that."

#### >> SLIDE 55

## Questions?