



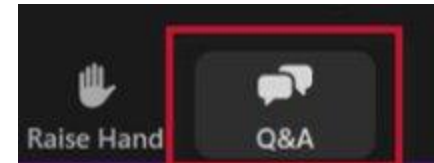
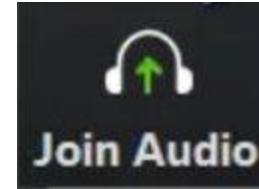
COMMIT TO
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Supporting Independence and Inclusion through a Community Participation Measure: A University and CIL Collaboration

April 21, 2023

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Presenters



Katie Clark, Policy Analyst, Office of Interagency Innovation, Administration for Community Living



Mark Salzer, PhD., Professor of Social and Behavioral Sciences; Director, Temple University Collaborative on Community Inclusion of Individuals with Psychiatric Disabilities

Vicki Smith, Executive Director, Alliance of Disability Advocates





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Commit to Connect Overview

Katie Clark

Administration for Community Living

About Commit to Connect

- Aim is to connect people living with isolation with programs and resources to build the social connections they need to thrive.
- Commit to Connect is funded primarily by the U.S. Administration for Community Living
- USAging serves as the Coordinating Center





Welcome to a Nationwide Network of Champions

Dedicated to Ending Social Isolation and Loneliness

Become a champion!



Connect

Connect with peers, expand your network, and make a difference.

Expand your network



Collaborate

Join in discussions, voice your opinion, and further your knowledge.

Tell your story



Explore

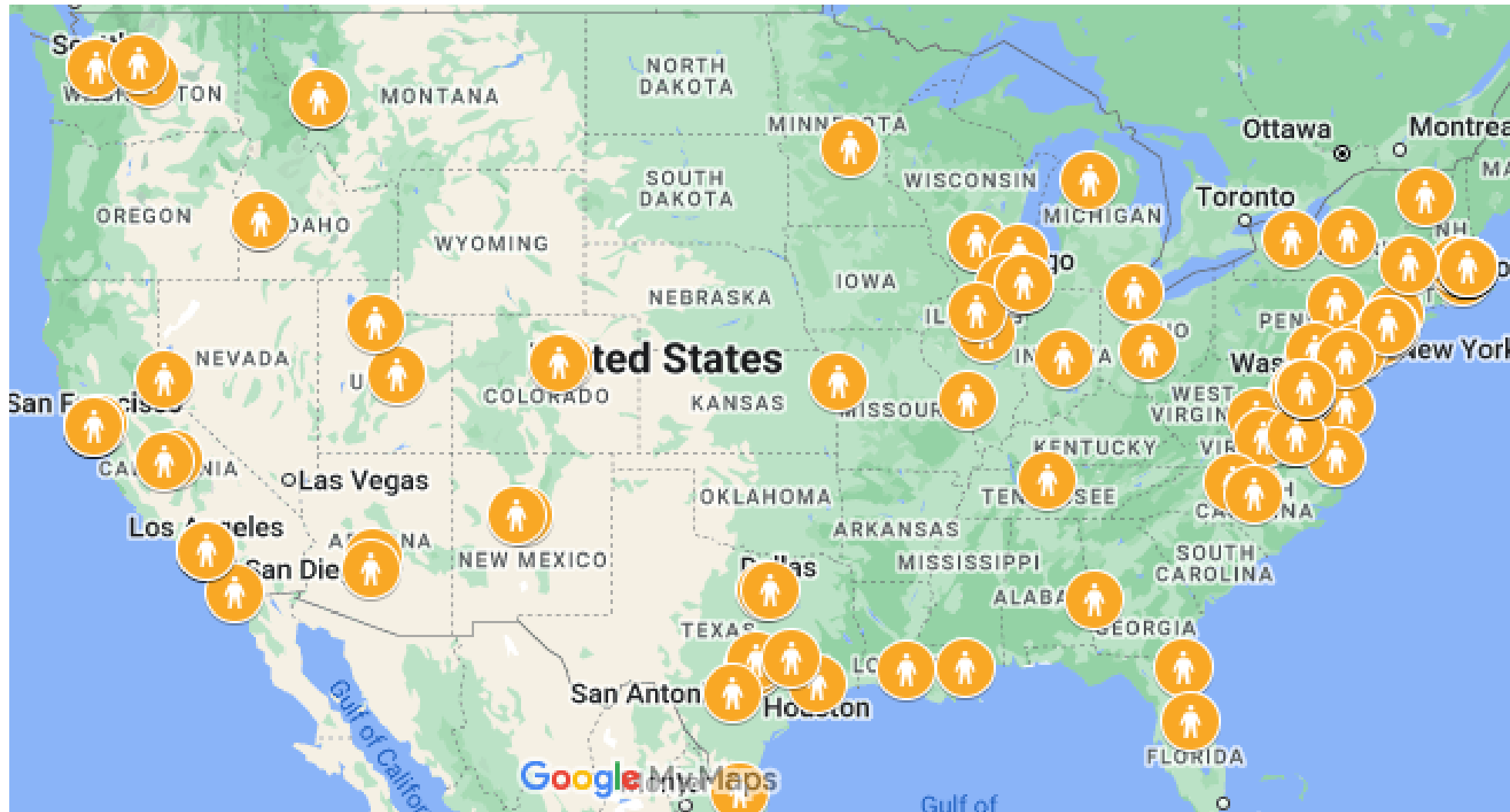
Explore, share resources, and inspire the work in your community.

Feed your inspiration



COMMIT TO Connect

NNoC includes 250+ members from across the U.S.





Social Engagement Virtual Summit

- This two-day virtual event will be held May 9 and 10, from 1:00-4:00 pm ET.
- More information on the event and how to register can be found here:
<https://www.engagingolderadults.org/2023-virtual-summit>



Commit to Connect Resources

- Sign up for our monthly newsletter: <https://committoconnect.org/> to learn about upcoming:
 - Topical Guides
 - Webinars
 - Peer to Peer Exchanges
 - Communities of Practice
 - And more!



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Introduction to Assessing Community Participation

Mark S. Salzer, Ph.D.

**Professor of Social and Behavioral Sciences, Temple University
Director, Temple University Collaborative on Community Inclusion**

For more information about these issues please go to
www.tucollaborative.org or send an email to msalzer@temple.edu

Disclosure and Acknowledgments

- I have no financial conflicts of interest to disclose associated with this presentation.
 - Temple University salary support over the past year includes:
 - NIDILRR; DOD; SAMHSA; NIH; PA BAS/Drexel University (ASERT/Commonwealth of PA); Delaware DHSS; NC DMHDDSAS (SAMHSA MHBG)
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On Community Inclusion of Individuals with Psychiatric Disabilities

Community Participation as a Medical Necessity



Well Together

A blueprint for community inclusion:
fundamental concepts, theoretical
frameworks and evidence

Prepared for Wellways Australia Limited by Mark S. Salzer and
Richard C. Baron from the Temple University Collaborative on
Community Inclusion of Individuals with Psychiatric Disabilities
(Philadelphia, PA, USA)

WELLWAYS AUSTRALIA



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On Community Inclusion of Individuals with Psychiatric Disabilities

Search: Well Together and Salzer

TUCP Measurement Development

- Temple University Community Participation (TUCP) measure: adaptation of the Group and Organizational Measure from a published study of the physical integration of persons with psychiatric disabilities (Wong et al., 2007).
- We knew very little about the community participation of people with significant mental health issues. I was not satisfied with the measures that were available.
- Added items based on feedback from individuals with significant mental health issues: “What types of participation are important to you?”
- Added questions about importance and sufficiency of participation.
 - Amount: How many days over the last 30 days did you do the following activity without a program staff person going with you..
 - Sufficiency: Do you do this activity? (Enough; Not enough; too much)
 - Self-Determination: Is this activity important to you? (Yes; No)



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TEMPLE UNIVERSITY COMMUNITY PARTICIPATION MEASURE

PARTICIPANT NAME: _____ **DATE:** _____

QUESTION 1: I am going to ask you about different activities you might have done **during the past 30 days** without a staff person going with you (i.e., someone from an agency or program you are in who is paid to help you). Please indicate the **number of days** during the **past 30 days** you have participated in each activity outside of your home without a staff person going with you **unless it is a personal assistant** or other similar type of support.

QUESTION 2: Do you do this activity, *Enough, Not Enough, or Too Much*? (circle the correct response)

- **INTERVIEWER NOTE:** If respondent has NOT done an activity in the past 30 days, the number of days would be 0. See the Library example below.
 - If respondent did NOT want to do the activity in the past 30 days, indicate: “Enough.”
 - If respondent wanted to go to the Library, but did the activity 0 times during the past 30 days select: “Not Enough.”

QUESTION 3: Is this activity important to you? (circle the correct response)

Example:

A. How many days during the past 30 days did you do the following activities without a program staff person going with you:	B. Number of Days (without a staff person)	C. Do you do this activity?			D. Is this activity important to you?	
		Enough	Not Enough	Too Much	Yes	No
9. Go to a library.	— <u>0</u> (# of Days)	1	2	3	1	0
24. Entertain friends in your home or visit friends in their homes.	— <u>5</u> (# of Days)	1	2	3	1	0



A. How many days during the past 30 days did you do the following activities without a program staff person going with you:	B. Number of Days (without a staff person)	C. Do you do this activity?			D. Is this activity important to you?	
		Enough	Not Enough	Too Much	Yes	No
1. Go shopping for pleasure or entertainment (e.g., at a grocery store, convenience store, shopping center, mall, other retail store, flea market, or garage sale.)	_____ (# of Days)	1	2	3	1	0
2. Go to a restaurant or coffee shop.	_____ (# of Days)	1	2	3	1	0
3. Go to a church, synagogue, or place of worship.	_____ (# of Days)	1	2	3	1	0
4. Go to a movie theater.	_____ (# of Days)	1	2	3	1	0
5. Go to a park or recreation center.	_____ (# of Days)	1	2	3	1	0
6. Go to a theater to watch a play, concert, dance, or other similar type of cultural event (not a movie theater).	_____ (# of Days)	1	2	3	1	0
7. Go to a zoo or botanical garden/arboretum.	_____ (# of Days)	1	2	3	1	0
8. Go to a library or museum.	_____ (# of Days)	1	2	3	1	0
9. Go to <u>watch</u> a sports event (including bowling, tennis, basketball, etc.).	_____ (# of Days)	1	2	3	1	0



A. How many days during the past 30 days did you do the following activities without a program staff person going with you:	B. Number of Days (without a staff person)	C. Do you do this activity?			D. Is this activity important to you?	
		Enough	Not Enough	Too Much	Yes	No
10. Go to a gym, health or exercise club, or pool, for leisure and recreation.	_____ (# of Days)	1	2	3	1	0
11. Engage in an organized sport (baseball, basketball, soccer game) or other organized physical activity (e.g., exercise class) outside the home.	_____ (# of Days)	1	2	3	1	0
12. Play games (e.g., chess, card, online gaming) outside the home, such as at a friend's house.	_____ (# of Days)	1	2	3	1	0
13. Play games, including online gaming, at your own home where you play with others (they may be physically present in your home or online).	_____ (# of Days)	1	2	3	1	0
14. Go to a barber shop, beauty salon, nail salon, or spa for enjoyment (i.e., you do it because you enjoy it and not because you simply need a haircut).	_____ (# of Days)	1	2	3	1	0
15. Use public transportation (buses, subway, trains).	_____ (# of Days)	1	2	3	1	0
16. Go to a social group in the community. For example, a book club, knitting group, or other group activity with people who have similar interests as you do.	_____ (# of Days)	1	2	3	1	0
17. Work for pay. This could be full- or part-time work.	_____ (# of Days)	1	2	3	1	0
18. Go to school to earn a degree or certificate (for example: GED, adult education, college, vocational or technical school, job training).	_____ (# of Days)	1	2	3	1	0



A. How many days during the past 30 days did you do the following activities without a program staff person going with you:	B. Number of Days (without a staff person)	C. Do you do this activity?			D. Is this activity important to you?	
		Enough	Not Enough	Too Much	Yes	No
19. Take a class for leisure or life skills (for example, classes for cooking, art crafts, ceramics, and photography).	_____ (# of Days)	1	2	3	1	0
20. Participate in volunteer activities (i.e., helping others or an organization without being paid).	_____ (# of Days)	1	2	3	1	0
21. Get together in the community or attend an event with family (for example, a wedding, bar mitzvah).	_____ (# of Days)	1	2	3	1	0
22. Get together in the community or attend an event with friends (for example, a wedding, bar mitzvah).	_____ (# of Days)	1	2	3	1	0
23. Entertain family in your home or visit family in their homes.	_____ (# of Days)	1	2	3	1	0
24. Entertain friends in your home or visit friends in their homes.	_____ (# of Days)	1	2	3	1	0
25. Hang out or socialize with people you know from school, work, the neighborhood, or other acquaintances.	_____ (# of Days)	1	2	3	1	0
26. Go to a community fair, block party, community clean-up day, or other community event or activity.	_____ (# of Days)	1	2	3	1	0
27. Attend or engage in civic or political activities or organizations (e.g., neighborhood watch or advocacy groups) or professional associations (e.g., conference or union meeting).	_____ (# of Days)	1	2	3	1	0



The following questions asks about your relationship with an intimate partner and you child(ren).

28. Are you currently married or in a domestic partnership/relationship (i.e., not married, but in a committed relationship or living with someone you are in an intimate relationship with)?	Yes	No				
29. If you <u>ARE NOT</u> currently married, in a domestic partnership, or living with an intimate partner (you answered “No” on question 28) please answer these questions...	A. How many days in the last 30 days did you get together with someone you consider to be a boyfriend/girlfriend?	B. Do you do this activity?			C. Is this activity important to you?	
How many days in the last 30 days did you get together with someone you consider to be a boyfriend/girlfriend?	_____ (# of Days)	Enough	Not Enough	Too Much	Yes	No
30. Are you a biological, adoptive, foster, or step parent?	Yes	No				
31. If you DO have children (“Yes” on Question #30), do you live with your child(ren)?	Yes	No				
32. If you have children (“Yes” on Question #30), but do NOT live with them (“No” on Question #30), please answer these questions...	A. How many days in the last 30 days have you gotten together with your child(ren)?	B. Do you do this activity?			C. Is this activity important to you?	
How many days in the last 30 days have you gotten together with your child(ren)?	_____ (# of Days)	Enough	Not Enough	Too Much	Yes	No



What Have We Learned About the Temple University Community Participation (TUCP) Measure:

“No one ever asks me these things.”



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On Community Inclusion of Individuals with Psychiatric Disabilities

The TUCP Has Good Psychometric Properties: It Works the Way We Would Hope It Would Work

- 1) Autistic People and people with psychiatric disabilities provide consistent answers over time on the TUCP measure (Test-retest reliability)
 - a) SA and IA both appear to be appropriate data collection methods
- 2) The TUCP measure results in similar responses as using a daily activity checklist (Intermethod Reliability)
- 3) Results using the TUCP are consistent with other measures in ways we would expect them to be consistent (Construct validity)



People are Not Participating As Much as they Would Like (Salzer et al., 2014, Rehabilitation Psychology)

	<u>Importance</u>		<u>Sufficiency</u>	
	<u>Yes</u>		<u>Less than you want</u>	
	<u>N</u>	<u>%</u>	<u>N</u>	<u>%</u>
Go shopping at grocery store?	114	96	32	28
Go to a restaurant or coffee shop?	81	68	38	47
Go to a church, synagogue, or place of worship?	90	78	53	59
Go to a movie?	67	56	47	70
Go to a park or recreation center?	84	72	40	48
Go to a theater or cultural event?	68	58	46	69
Go to a zoo, botanical garden, or museum?	60	52	43	72
Go to run errands?	105	88	19	18
Go to a library?	80	67	46	58
Go to watch a sports event?	65	55	41	63
Go to a gym?	85	71	56	66
Go to a barber shop, beauty salon, nail salon, spa?	91	76	44	48
Use public transportation?	109	92	20	18
Go to a 12-step grp for mental health issues?	78	66	28	36
Go to a 12-step grp for substance use problems?	48	40	15	31
Go to another type of support group?	43	36	16	37
Go to a consumer-run organization?	50	42	30	60
Go to a social group in the community?	59	50	38	64
Work for pay?	83	71	54	65
Go to school to earn a degree or certificate?	75	63	51	68
Take a class for leisure or life skills?	59	50	38	64
Participate in volunteer activities?	81	68	34	42
Get together in the community or attend an event with family or friends?	85	72	41	48
Entertain family or friends in your home or visit family or friends?	95	81	50	53
Go to a community fair, community event or activity?	72	61	41	57
Go to or participate in civic or political activities or organizations?	53	45	36	69



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People with SMI participate much less than the general population (Nagata et al., 2020)

- Fewer participation days
- Less likely to participate in important areas
- Less satisfied with the degree to which they participate (42% sufficiency vs 59%)



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Getting Out and About is Good for Health

	% time at home	% time alone
U.S. Population	54%	41%
People with serious mental illnesses	75-80%	<u>55-75%</u>

- “Getting out and about” is beneficial for health
 - More community participation is associated with more physical activity (Snethen et al., 2021)
 - Greater participation is associated with lower levels of depression (Nagata et al., 2021; 2022)
- A few other things we have learned about community participation using the TUCP
 - Living in Urban Areas is Associated with Greater Participation (Townley et al., 2017)
 - Car Access Affects Participation in Urban and Non-Urban Settings (Townley et al., 2018)



Autistic Adults Participate Less Than the General Population in Desired Areas

Table 2 Unadjusted and covariate-adjusted descriptive statistics for community participation outcomes

	Unadjusted				t value	Covariate-adjusted				F value
	ASD		General population			ASD		General population		
	M	SD	M	SD		M	SE	M	SE	
Total number of participation days	30.10	33.02	62.67	32.63	- 14.62**	31.76	1.49	61.65	2.79	66.08**
Total number of important areas	9.96	5.29	14.03	4.16	- 11.99**	10.13	0.23	13.84	0.43	43.52**
Breadth	4.27	4.02	8.67	3.45	- 16.80**	4.54	0.17	8.39	0.33	79.52**
Breadth ratio	0.45	0.35	0.63	0.19	- 8.62**	0.47	0.01	0.62	0.03	17.88**
Sufficiency ratio	0.50	0.33	0.59	0.24	- 4.18**	0.51	0.02	0.58	0.03	3.94*

Covariates for adjusted analysis included age, sex, race/ethnicity, urbanicity, and education level

N=~700 from PA Statewide survey

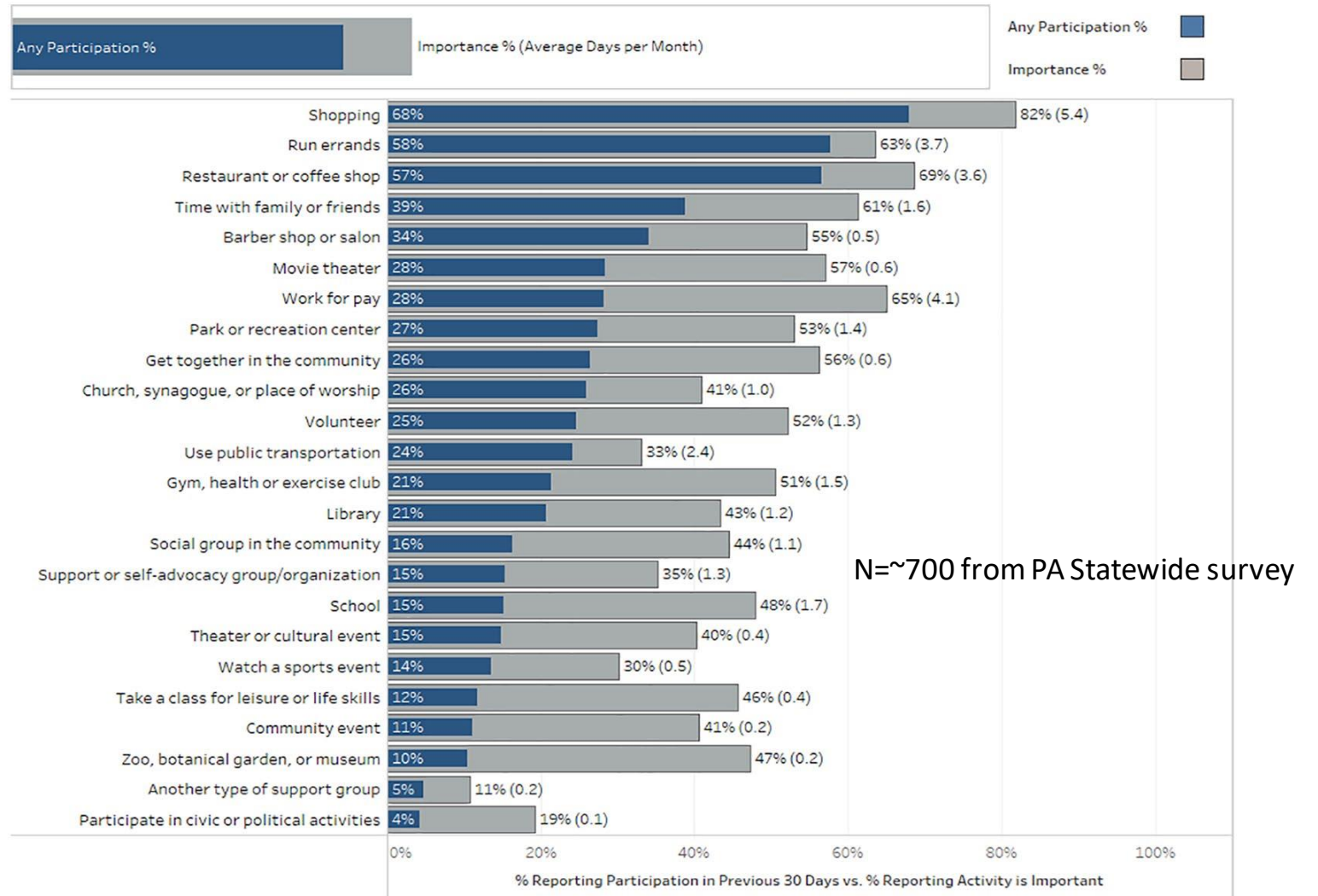


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Song, W, Salzer, M.S., Nonnemacher, S.L., Brusilovskiy, E, Townley, G., & Shea, L. (2022). Community participation comparison between adults on the autism spectrum and adults in the general population. *Journal of Autism and Developmental Disorders*, 52(4), 1610-1621. doi: 10.1007/s10803-021-05059-9.

Autistic Adults Participate Infrequently in Areas that Are Important to Them



Shea, L., Verstrete, K., Nonnemacher, S., Song, W., & Salzer, M.S. (2021). Self-Reported Community Participation Experiences and Preferences of Autistic Adults. *Autism, 25*(5), 1295-1306. doi:10.1177/1362361320987682.



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Factors Associated with Participation of Autistic Adults

- Comorbidities (Shea et al., 2021)
 - Autistic adults with ID participate less than those without ID
 - Autistic adults with a co-occurring psychiatric diagnosis participate less and are less satisfied with their participation than those without
- Transportation (Song et al., 2023)
 - Access to more transportation modes (e.g., driving, public transportation, rides, and walking) is associated with more participation
 - Driving is related to enhanced participation
 - Those who are solely dependent on others to get around had poorer participation outcomes compared to those who used more independent transportation options
- Living arrangements (Song et al., 2022)
 - After controlling various sociodemographic factors known to be associated with community participation...
 - Autistic adults living independently participated more in community activities than those living with family or in a supported living facility, but experienced less satisfaction with their participation

Shea, L., Verstrete, K., Nonnemacher, S., Song, W., & Salzer, M.S. (2021). Self-Reported Community Participation Experiences and Preferences of Autistic Adults. *Autism*, 25(5), 1295-1306. doi:10.1177/1362361320987682.

Song, W., Salzer, M.S., Pfeiffer, E., & Shea, L. (2023). Transportation and Community Participation among Autistic Adults Inclusion. *Inclusion*, 11(1), 40-54. DOI: 10.1352/2326-6988-11.1.40

Song, W., Salzer, M.S., Nonnemacher, S., Koffler Miller, K., & Shea, L. (2022). Living Arrangements and Community Participation Among Autistic Adults: Exploring the Possible Influences of Living Alone or With Others. *Research in Developmental Disabilities*, May; 124: 104213. doi: 10.1016/j.ridd.2022.104213.



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Why Use the TUCP As an Assessment Tool?

- People do not respond well when simply asked – “What do you like to do?” or “What would you like to do more of?”
- Going through a list does the following:
 - Reminds people about things they may have done, or like to do, but have not done for awhile or have been told they can no longer do it
 - Assists the person doing the assessment in making sure they ask questions about all areas of participation that are meaningful to people.



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Needs of TCL Participants

- TCL participants identify an average of 18 participation areas as important to them
 - Counters the notion that these folks have limited interests
- TCL participated “enough” in only 14% of the areas (about 1.5 areas out of 10) they identified as important
 - Among the lowest sufficiency rate ever seen using this measure
 - Limited participation was seen in every area



Thank You!!

Feel free to contact me at
msalzer@temple.edu

Checkout our website:
www.tucollaborative.org




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Historical Context to Transition to Community Living

Around 2009 Disability Rights NC investigated the placement of people with mental illness in Adult Care instead of state operated facilities in a failed effort to comply with the Americans with Disabilities Act.

In August 2010 Disability Rights NC issued a report titled Trapped in a Fractured System of Care while simultaneously filing an Olmstead Complaint with the US DOJ.



Trapped in a Fractured System

People with Mental Illness in Adult Care Homes

SPECIAL REPORT: AUGUST 2010

DISABILITY RIGHTS
NORTH CAROLINA
Champions for Equality and Justice

North Carolina's Protection and Advocacy

www.disabilityrightsnc.org

2626 Glenwood Avenue
Suite 550
Raleigh, North Carolina 27608
919-856-2195
919-777-235-4210
919-888-268-5535 TTY
919-856-2244 fax

The Power of Olmstead

- US DOJ subsequently conducted their own investigation and confirmed DRNC findings that NC was out of compliance with the Olmstead Decision.
- The State of North Carolina entered into a settlement agreement with the United States Department of Justice in 2012
- NC agreed to develop and implement effective measures to prevent inappropriate institutionalization and to provide adequate and appropriate public services and supports identified through person centered planning in the most integrated setting appropriate to meet the needs of individuals with SMI, who are in or at risk of entry to an adult care home by July 1, 2020.

Services to be Developed in the Settlement

Community Based Housing Slots

Community Based Mental Health Services

Supported Employment

Discharge and Transition Services

Preadmission Screening and Diversion

Quality Assurance and Improvement Performance Assurances

NC has not met the terms and conditions of the settlement nine years later

What We Know About Successful Transitions To Community

- Successful transitions from state hospitals or any institutional setting should focus on more than access to treatment and medications
- Supported housing research has shown that people with significant impairments can be housed, but suggests that enhanced community tenure will require supporting people in engaging in their communities
- At Intake, we ask our consumers what they want to do in the community.
- Individuals connected to or engaged in community activities are more likely to stay out of institutional settings.

Link: <https://www.youtube.com/watch?v=MzYQeLA7BlI>



Overview of engAGED

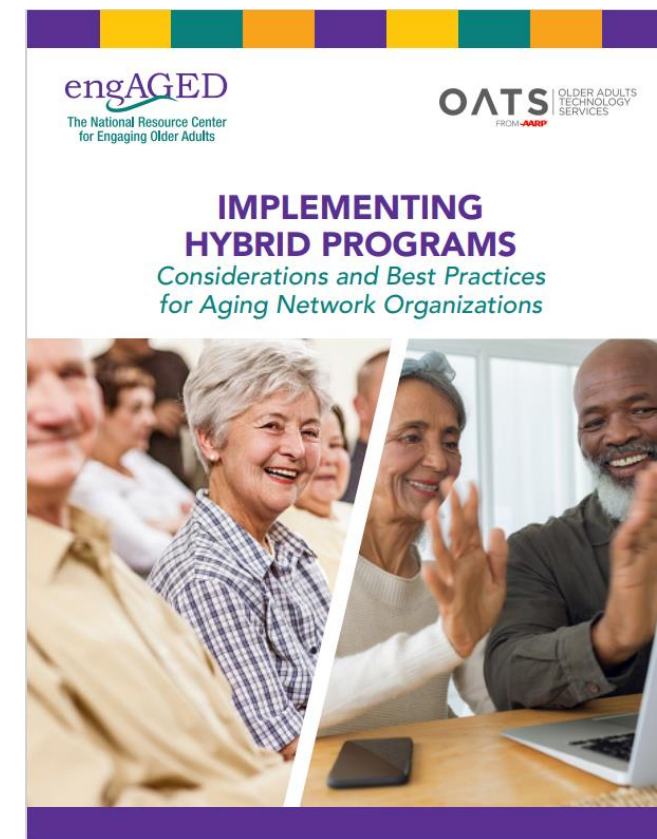
- National effort to increase social engagement of older adults, people with disabilities and caregivers
- Administered by USAging
- Funded by the U.S. Administration for Community Living

www.engagingolderadults.org



engAGED Resources

- New! A manual on Implementing Hybrid Programs
- Updated! A re-launched and updated Community Awareness Toolkit
- Other resources:
 - Social Engagement Innovations Hub
 - Tips for holding Virtual Events manual
 - Videos
 - Consumer brochures
- Monthly newsletter and blog
- www.engagingolderadults.org





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Questions and Discussion

Please submit your questions or
comments through the Q&A.

Thank you!

- Please complete the survey which will be displayed in your browser after Zoom closes. There is also a brief 3-month survey.
- The recording will be available on www.committoconnect.org

For further questions, contact us at:
info@committoconnect.org

