Current outcomes of formerly institutionalized and never-institutionalized adults

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Acknowledgements

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- Points of view or opinions do not necessarily represent official NIDILRR policy.

DATA SOURCE

- This study involved secondary analysis of US **2018-19 National Core Indicators In-Person Survey (NCI-IPS)** data analyzed in this study (**pre-COVID**).

- We are grateful to the *National Association of State Directors of Developmental Disabilities Services* (NASDDDS), the *Human Services Research Institute* (HSRI) for granting access to these data.

Deinstitutionalization Research

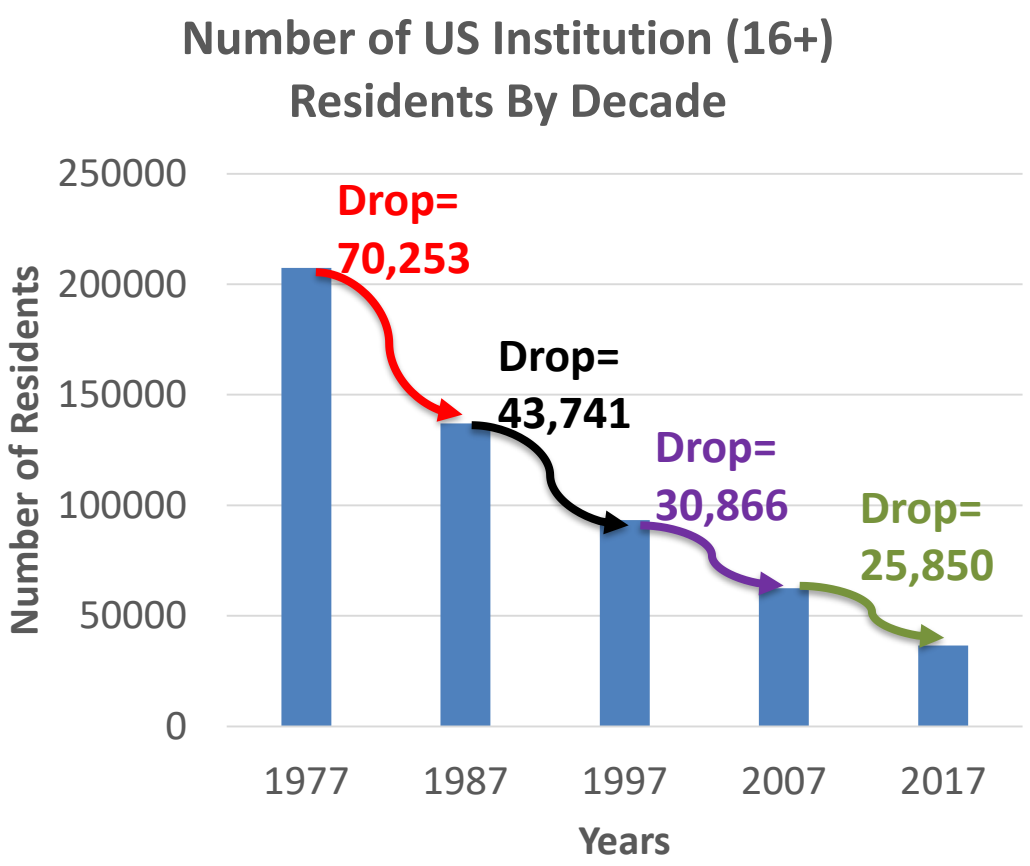
- Evaluating deinstitutionalization has involved
  - contrasts between ***movers*** **and *stayers***
  - longitudinal ***before and after*** **comparisons**

- First comparison of ***formerly institutionalized*** *and* ***never institutionalized*** adult IDD service users.

History of Institutionalization
NCI®-IDD 2018-19 Data

- **"Has person ever lived (longer than a year) in an institutional setting?"**
- 35 US states (of 37 participating) reported data on history of institutionalization.
  - Excluded 6 states with >25% missing data, leaving a 29-state sample.
- Excluded current institution residents (*n*=573)
- **13,820** adult (18+) users of US IDD services
  - **2137** (**15.5%**) had been institutionalized for 1 year or more.
- **Major differences in personal characteristics** between those with vs. without a personal history of institutionalization.

Most US former institution dwellers (16+ residents) moved to the community decades ago (source Larson et al., 2022, Table 3.2)



Most former institution residents moved to the community **decades ago**, so are:

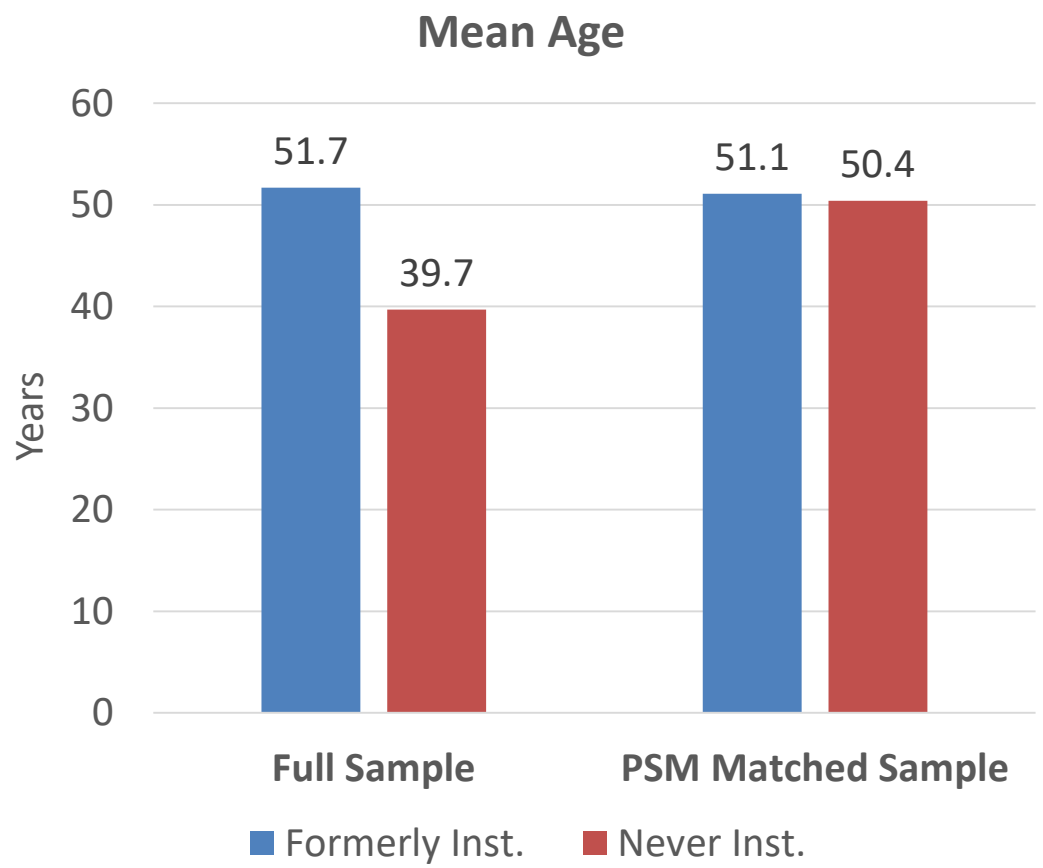
- Older
- More disabled (e.g., mobility)

than IDD service users who were never institutionalized and mostly joined the adult service system more recently.

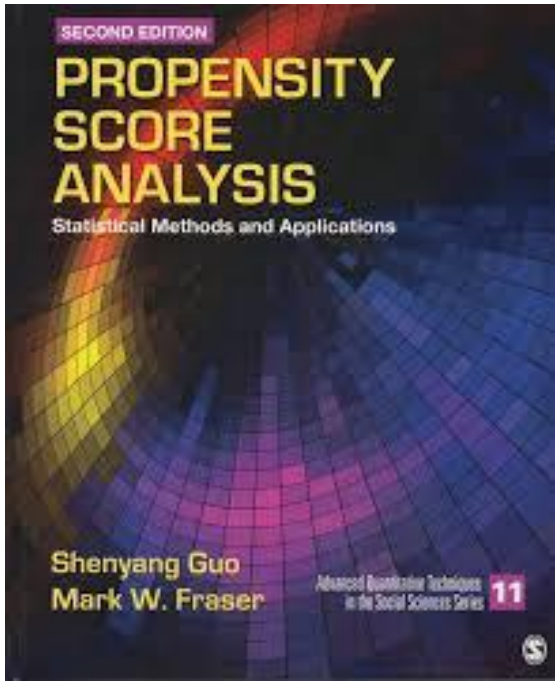
- Likely moved to **the *type* of community service** (e.g., group home) **available when they moved out of the institution**.

Propensity Score Matching (PSM)

Matching keys: age group, sex, level of ID, challenging behavior, mental health, mobility

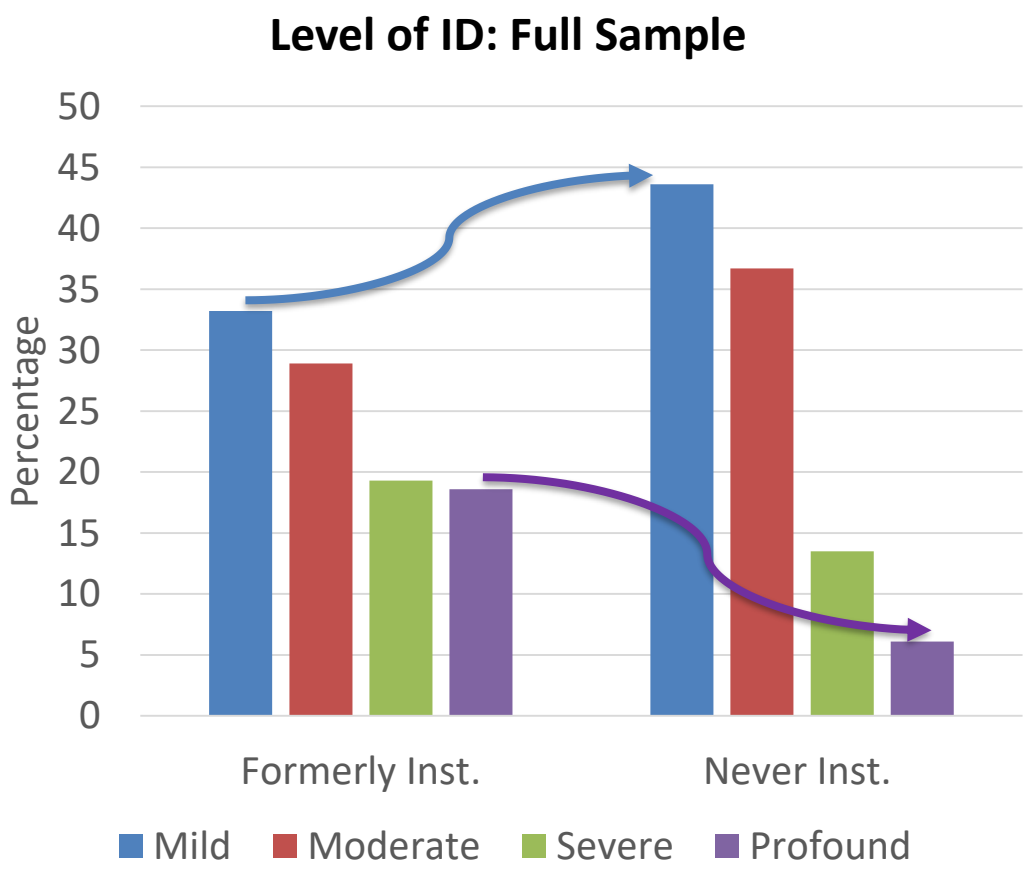


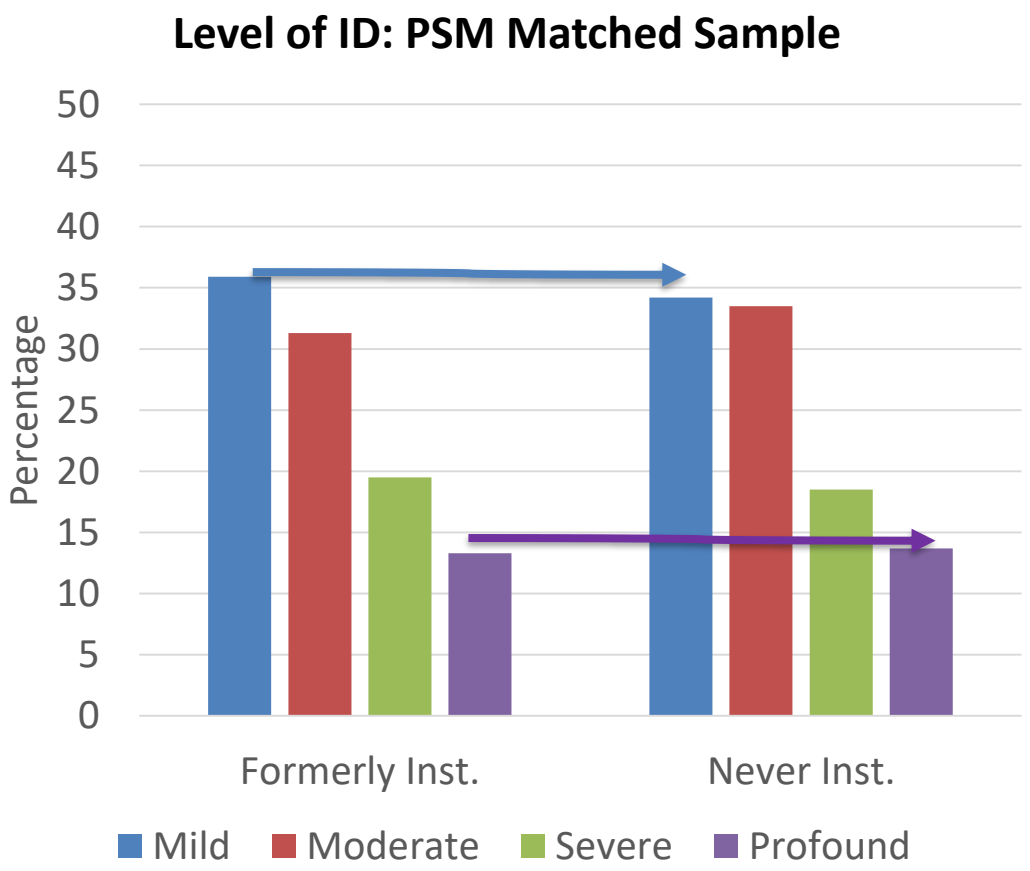
Individual matching based on the propensity score, calculated using **6 matching keys**.



Propensity Score Matching (PSM)

6 **Matching keys:** age group, sex, **level of ID,** challenging behavior, mental health, mobility





Propensity Score Matching (PSM)

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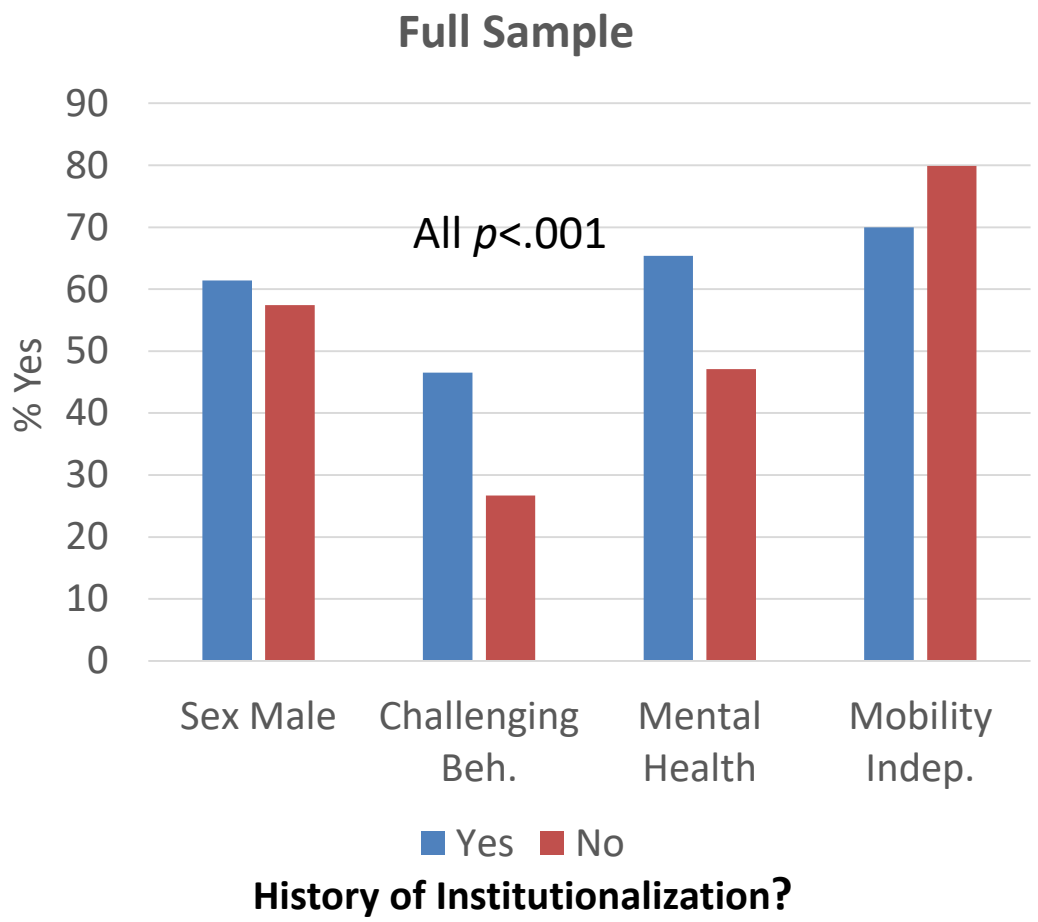
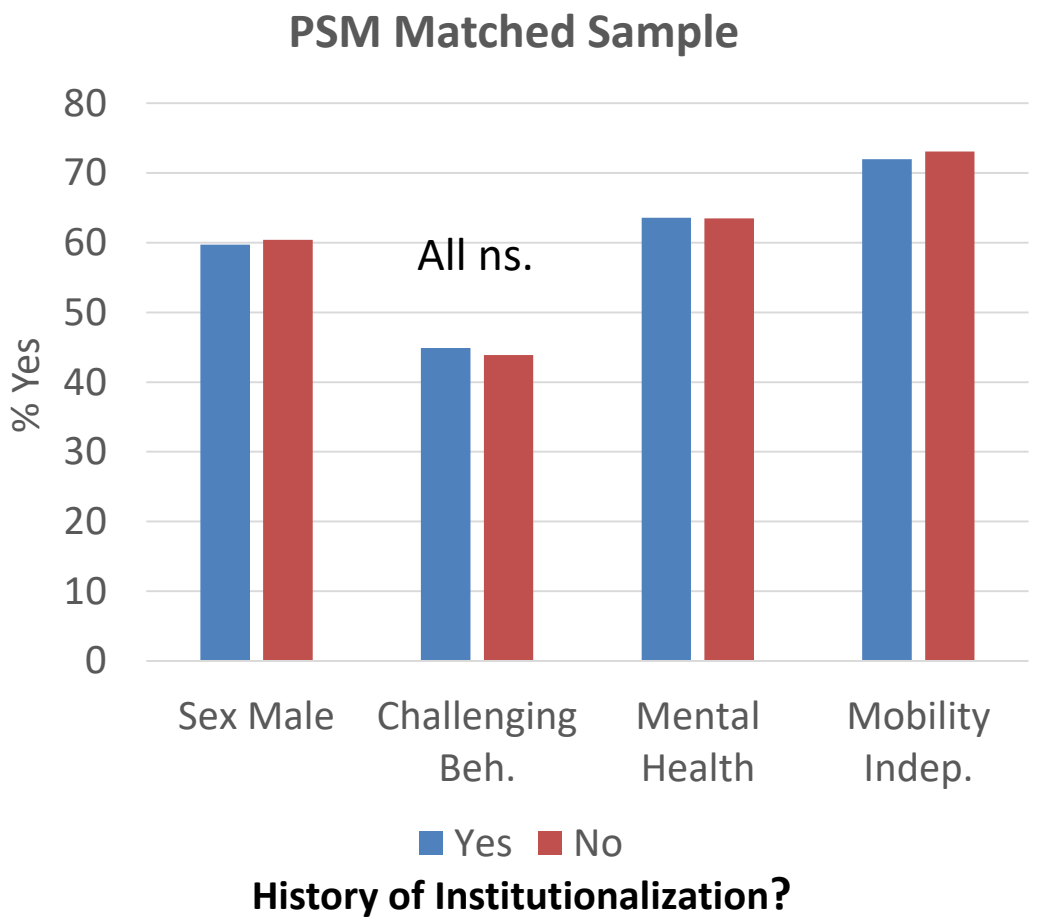




Outcomes: Cross-sectional comparisons

All outcome analyses use the PSM sample (*N*=3,376)

SERVICE OUTCOMES

- Living arrangements
- Employment and day activities

PERSONAL OUTCOMES

- Choice
- Social network, loneliness and community participation
- Group treatment

- We reported 19 comparisons so we used Bonferroni adjustment of alpha of 0.05/19 or

  ***p*<0.003.**

Outcomes: Formerly institutionalized vs. never institutionalized

10 significant (*p*<.003) differences favoring *Never Institutionalized*

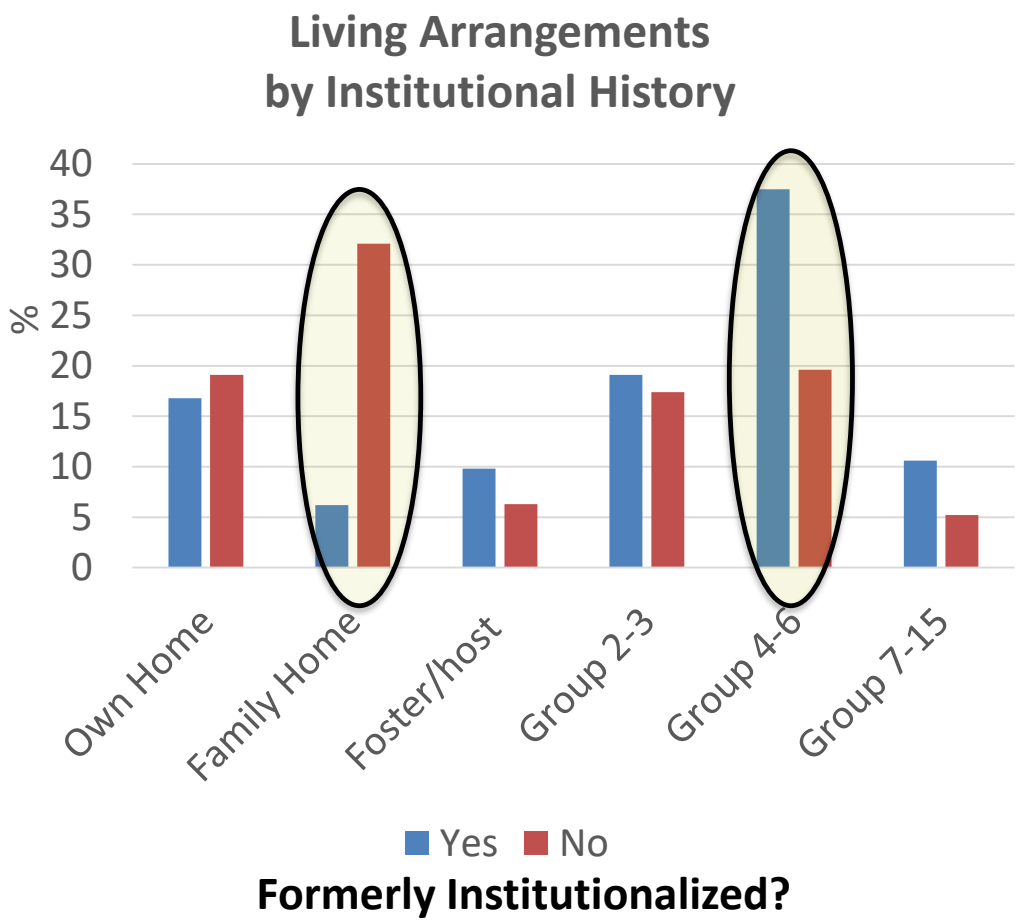
- Living arrangements
- *Facility-based day activities*
- Support-related choice
- *Less loneliness*
- Companions at community groups and religious services (6 outcomes)

- **0 significant (*p*<.003) differences favoring *Formerly Institutionalized***

- 9 0utcomes – between group differences **not significant** at *p*<.003

Living Arrangements

Chi squared = 435.83, *p*<.001



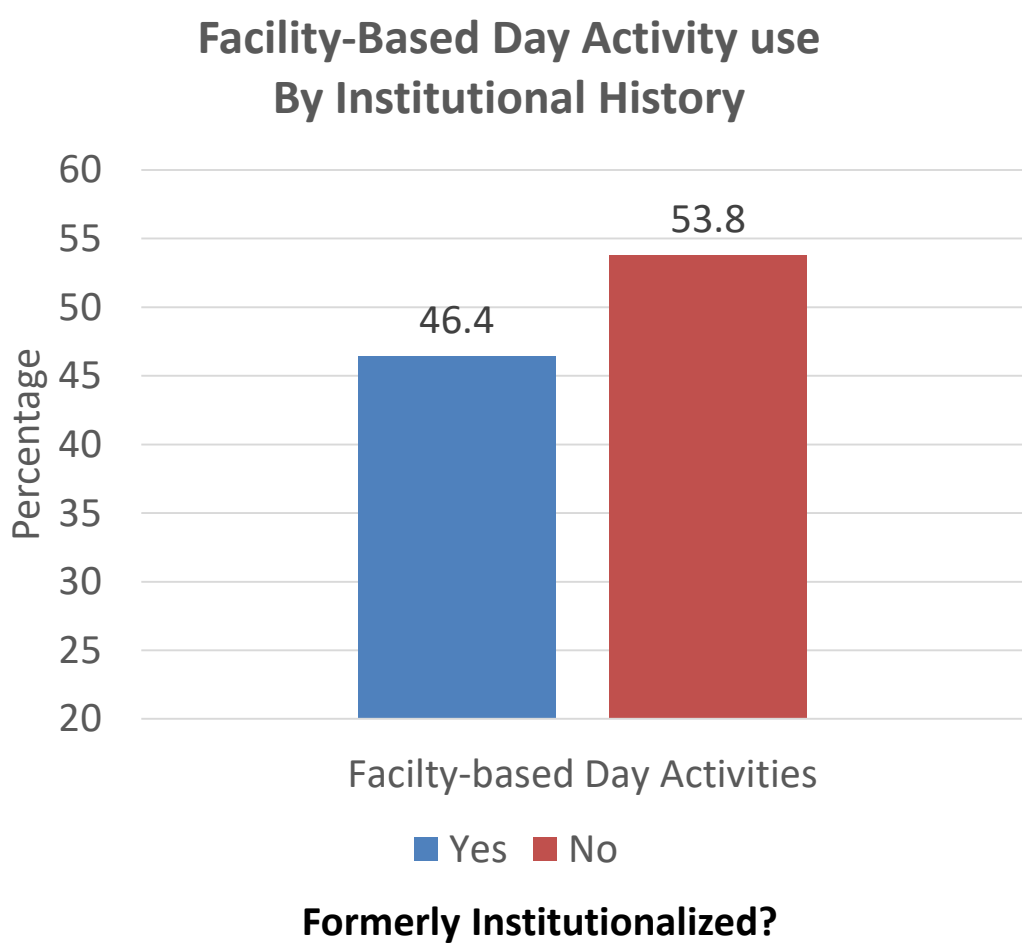
- Former institution residents remained in a more **restrictive, congregate** community living settings decades after leaving the institution.

Employment and day activities

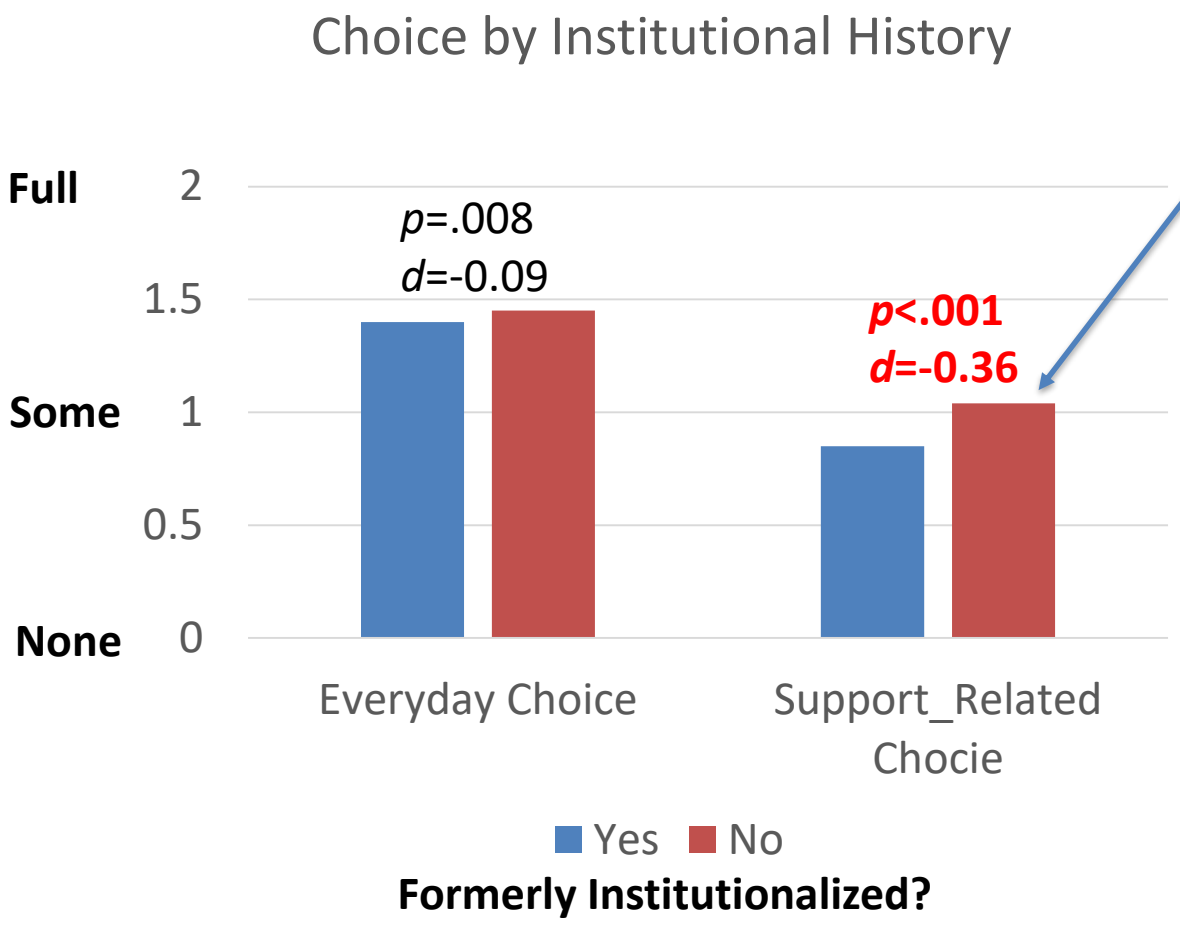
No significant differences for

- Community employment
- Facility-based employment
- Community day activities
- No formal day activities.

Chi squared = 17.92, *p*<.001, *d*=-0.15



Choice



Support related choice:

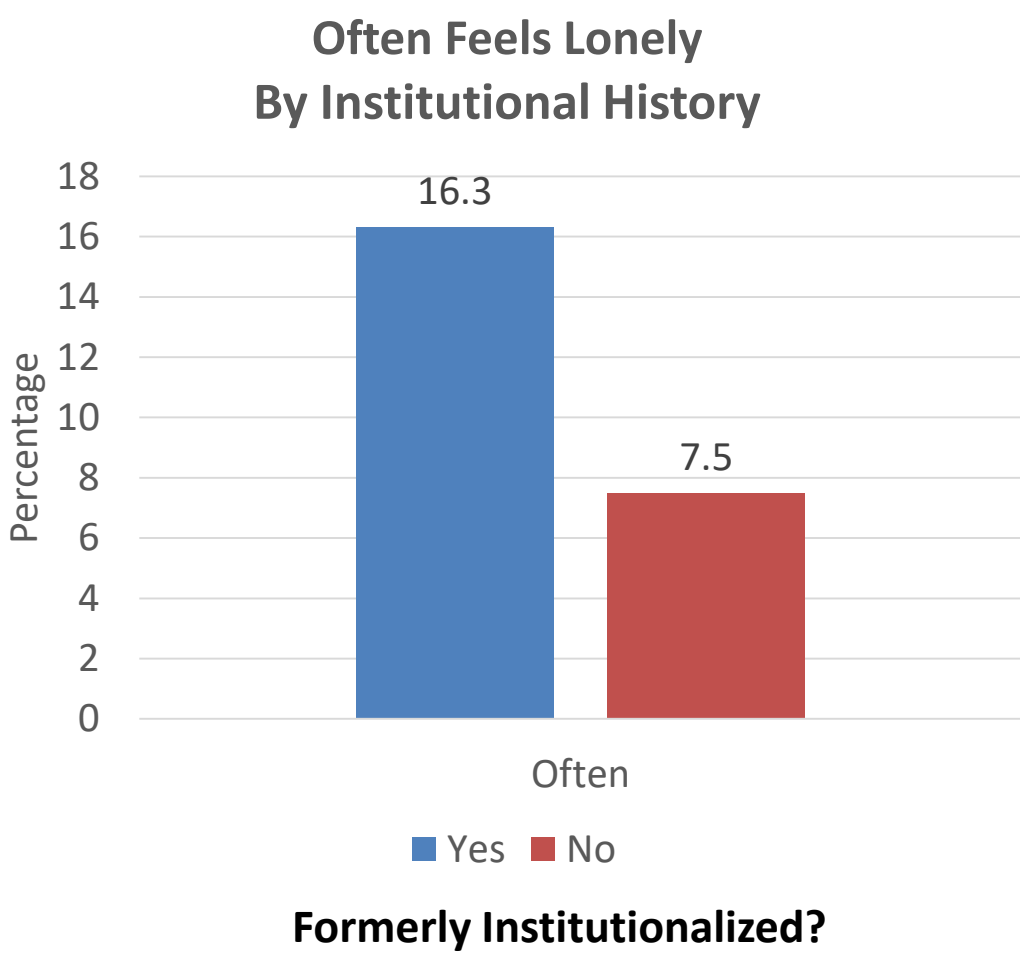
- Where to live
- People you live with
- The place you work, your day program or workshop
- Changing your case manager
- Your staff.

Feels lonely

- Formerly institutionalized participants were **significantly more likely to report often feeling lonely.**

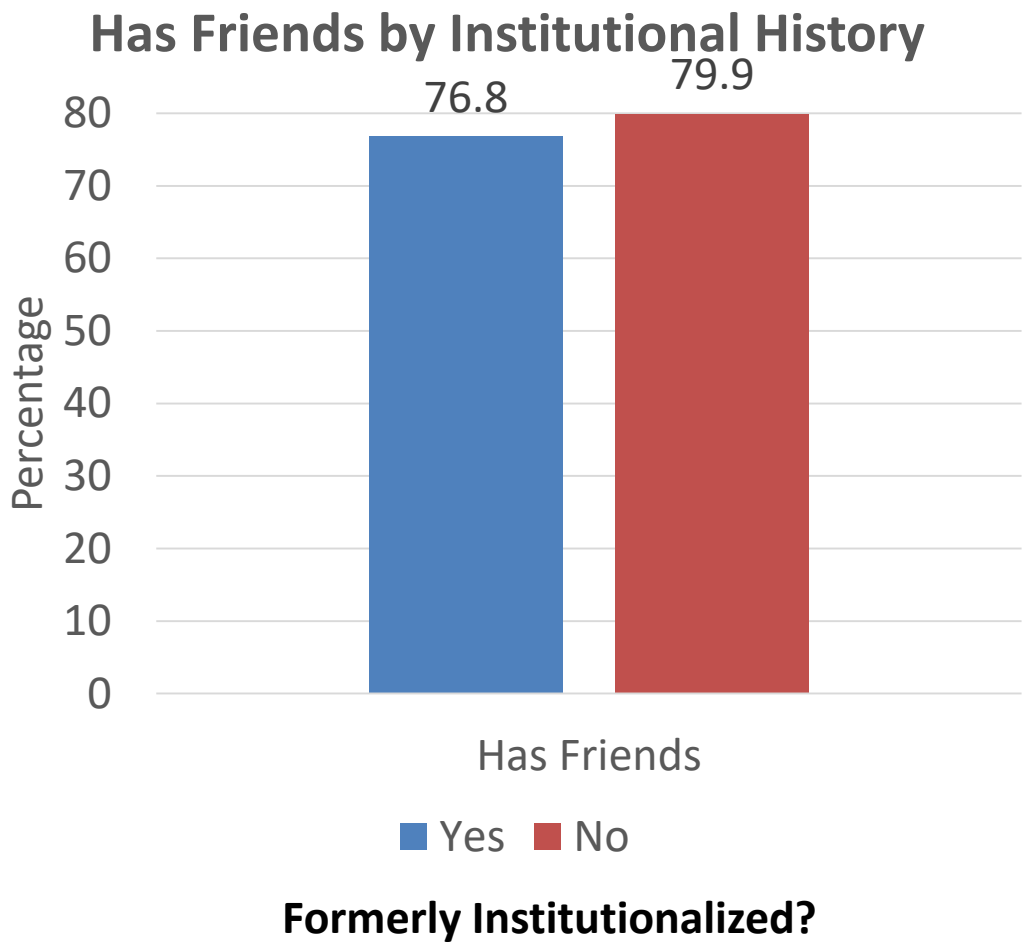
- Research shows that **loneliness is strongly related to poor physical and mental health**.

Chi squared = 40.21, *p*<.001, *d*=0.21



Having friends (other than family and staff)

- Having friends did not differ significantly by group.



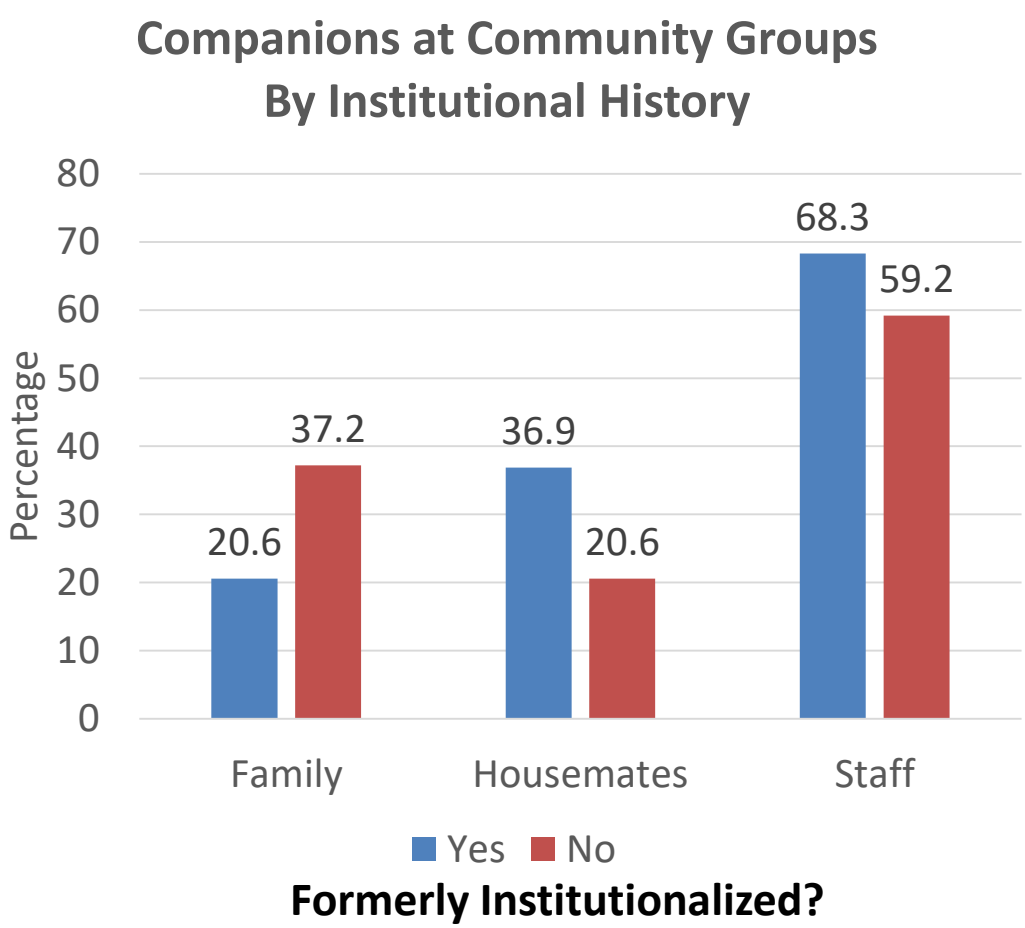
Mainstream Community Group Membership and Companions

Percentage participation in mainstream community groups did **not differ** significantly:

- Formerly institutionalized (32.2%)
- Never institutionalized (30.8%).

- **Companions** at the group differed significantly.

All $p<.003$



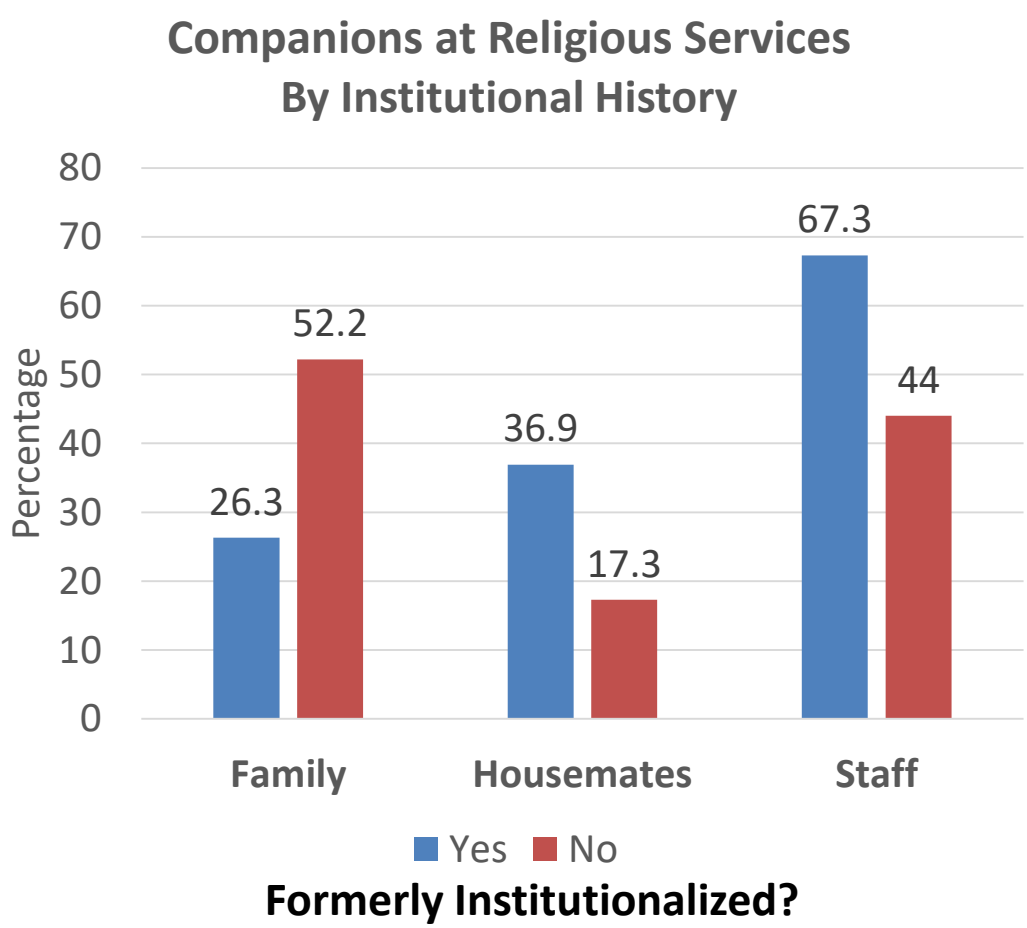
Religious Service Participation and Companions

Percentage participation in religious services did **not differ** significantly:

- Formerly institutionalized (53.9%)
- Never institutionalized (57.2%).

- **Companions** at religious services differed significantly.

All *p*<.003

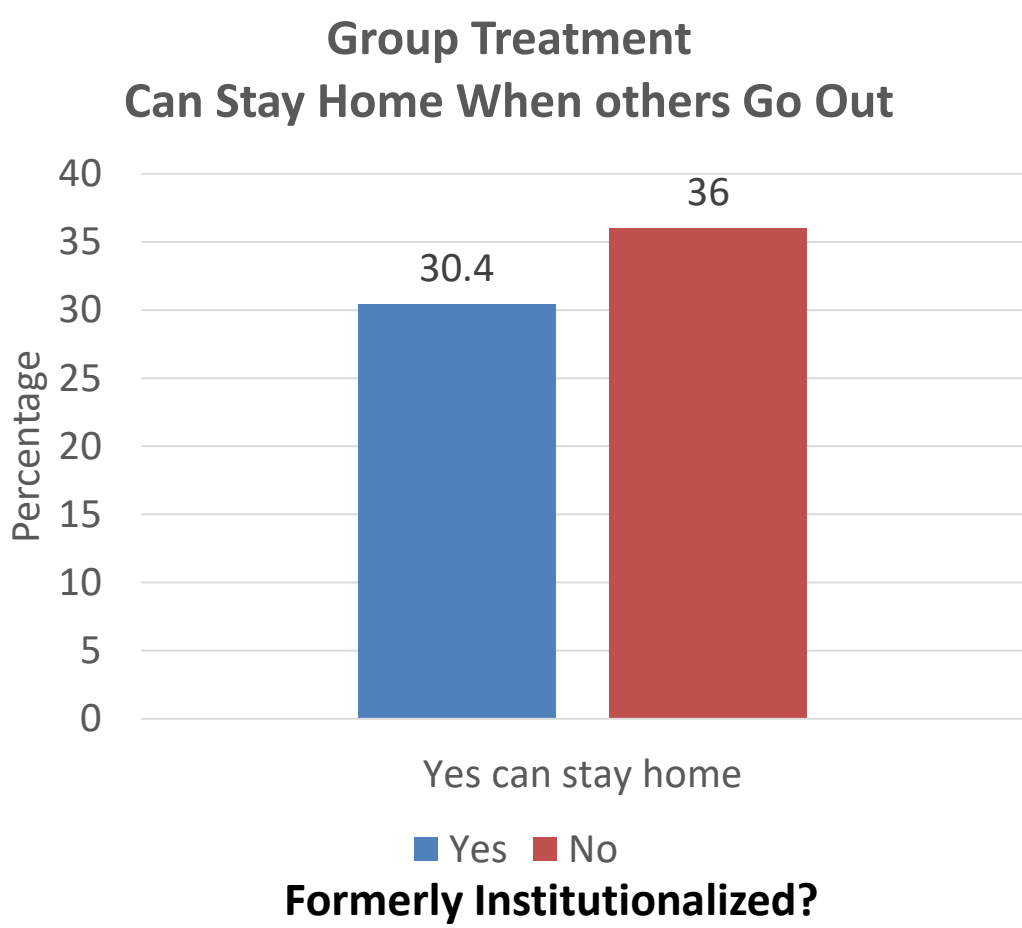


Group treatment

'(If not currently living alone) when people in your house go somewhere, do you have to go too, or can you stay at home if you want to?'

- More never institutionalized people could stay home if they wanted.
- This comparison did not quite attain significance at *p*<.003.

***p*=.004 so nonsig.**



Conclusions

Many former institution residents remain **disadvantaged long term** relative to their peers and **live a more service-focused life** as reflected in:

- their **congregate living** arrangements
- having **less choice**
- greater reliance on housemates and disability staff as **companions** for community participation
- more **feeling lonely**.

Limitations and Implications

LIMITATIONS

- *Matching* on *current* characteristics may have obscured some effects of institutionalization (e.g., challenging behavior, mental health).

- No data on:
  - *length of institutionalization*
  - *how recently* each person left the institution
- so it is unknown whether these factors were related to outcomes.

IMPLICATIONS

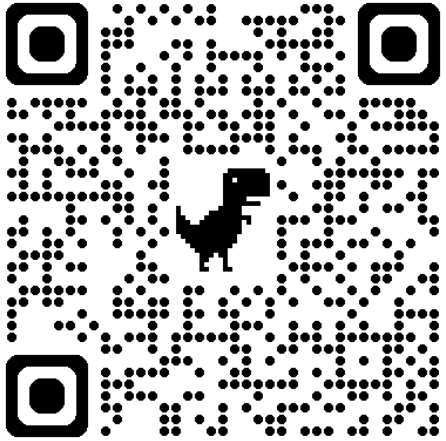
- How to **enhance QoL** in the community *following deinstitutionalization*.

For current institution residents:

- How to ensure they
  - move to ***individualized*** community living arrangements
  - have strong ***social connections*** outside of the service system (with family, friends, community members)

References

Stancliffe, R. J., Tichá, R., Pettingell, S. L., Houseworth, J., & Bershadsky, J. (2023). Current services and outcomes of formerly-institutionalized and never-institutionalized US adults with intellectual and developmental disabilities: A propensity score matching analysis. *Journal of Applied Research in Intellectual Disabilities*, *36*(4), 859-870. https://doi.org/10.1111/jar.13103 Published open access.



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