



THE UNIVERSITY OF
SYDNEY

**RESEARCH AND TRAINING CENTER
ON COMMUNITY LIVING**
UNIVERSITY OF MINNESOTA



Choice of where and with whom to live

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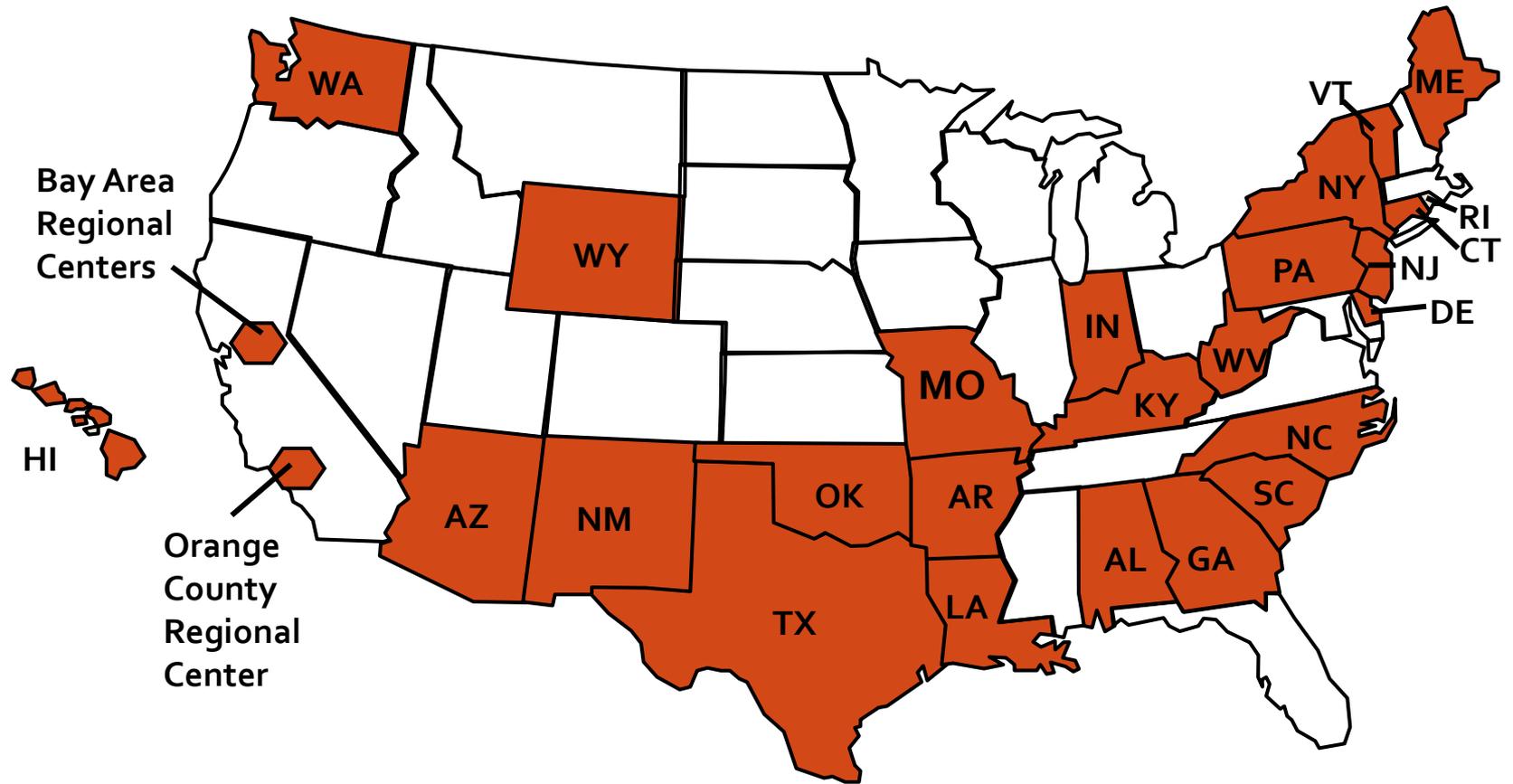
Rights

- Article 19a of the UN Convention on the Rights of Persons with Disabilities (United Nations, 2006) states:
 - *“Persons with disabilities have the opportunity to choose their place of residence and **where and with whom they live** on an equal basis with others and are not obliged to live in a particular living arrangement”.*



Rights and Dignity of Persons with Disabilities

26 Participating States 2007-08



Participants

- **6,778 adult** developmental disabilities service users living in **non-family-home** service settings in **26** states participating in the National Core Indicators (NCI) program (see Stancliffe et al., 2011).
- Potential participants living with natural or adoptive family members were excluded because people in those settings were not asked about choosing where and with whom they live.



NCI Questions on Choice of Living Arrangements

- Key NCI choice items about the person's current living situation were:

Who chose (or picked) the place where you live?

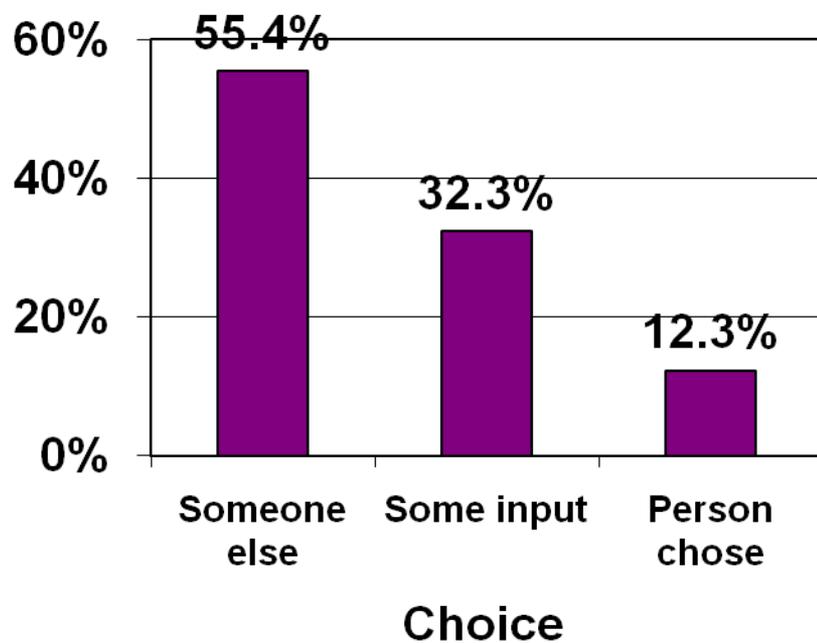
- Person chose without help
- Person had some input
- Someone else chose.

Did you choose (or pick) the person / people you live with (or as appropriate, Did you choose to live by yourself)?

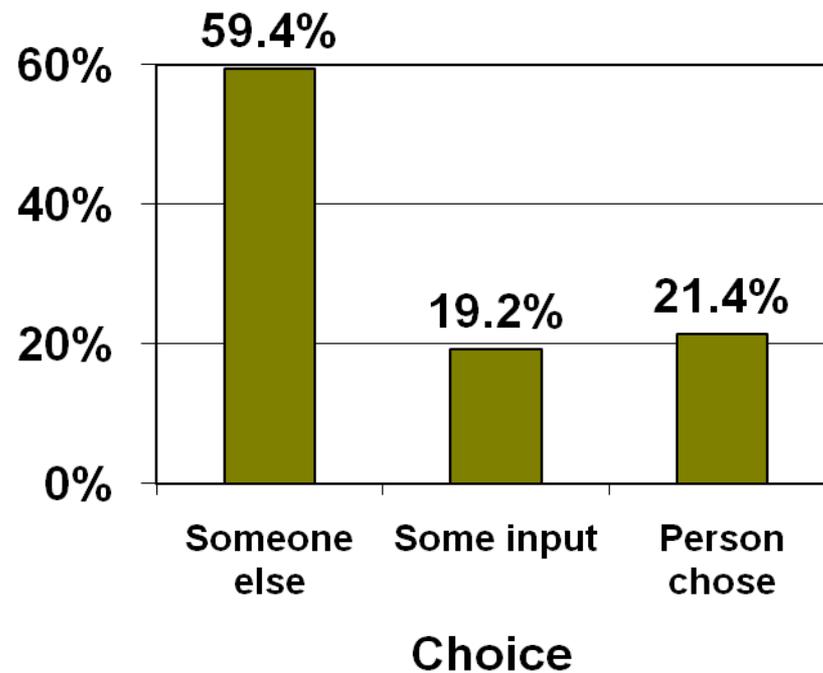
- Yes, chose people s/he lives with or to live alone
- Chose some people or had some input
- No, someone else chose.

Overall NCI Choice Results 2008

Choosing Where to Live



Choosing With Whom to Live

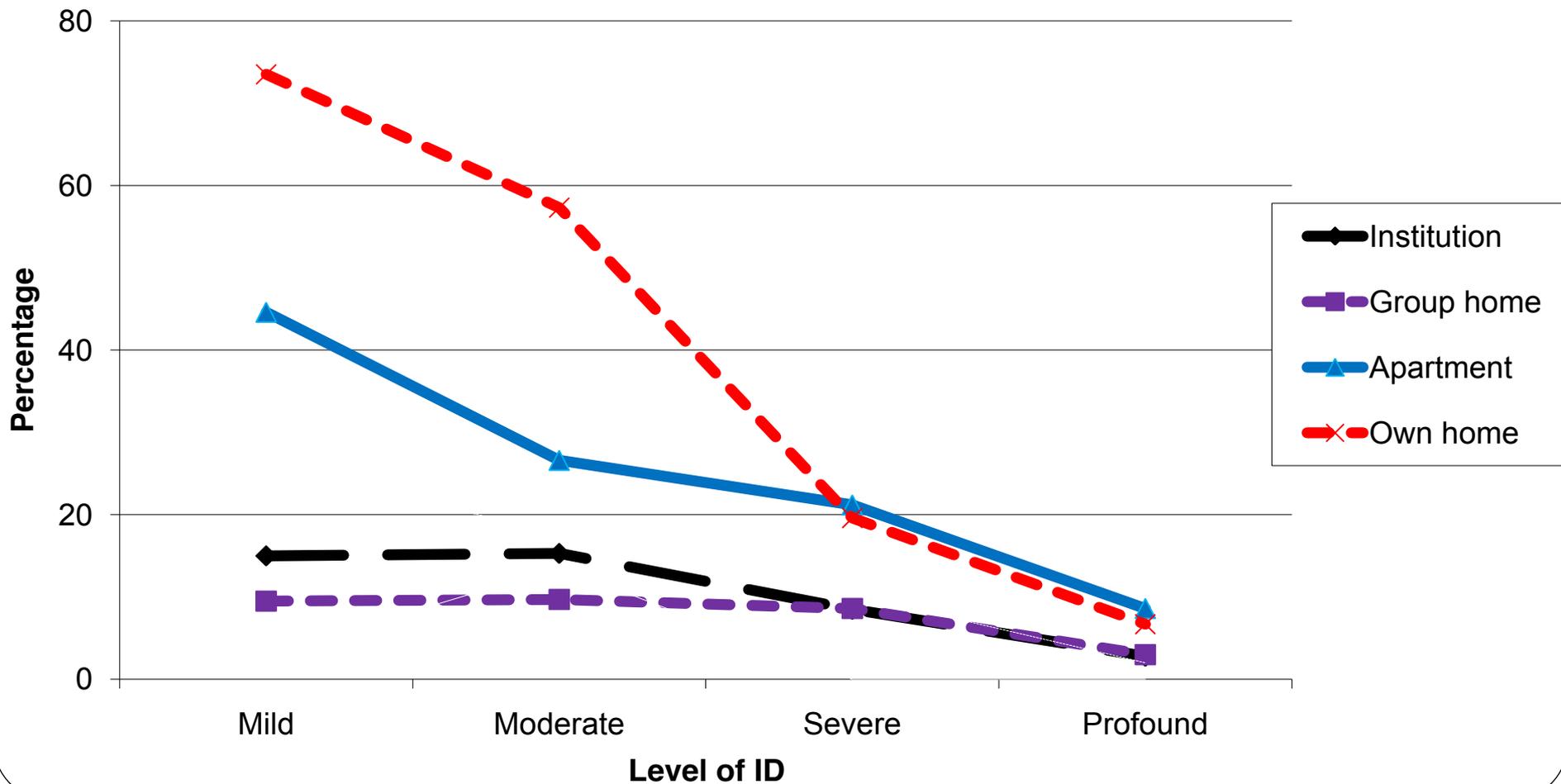


Conclusions

- In 2008 choices about where and with whom to live were not made by the *majority* of participants.
- There was greater choice of living companions than choice of where to live.



Choosing *Whom to Live With* (without help) by Level of Disability and Residence Type



Conclusions

- **People with mild intellectual disability**
 - wide variation in choice of living companions by residence type
 - own home (73.5% chose without help)
 - group home (9.5% chose without help)
 - seemingly reflects the real-world availability of choice of living companions in the different residence types.
- **Participants with more severe disability**
 - little choice of whom to live with, regardless of residence type
 - participants with profound intellectual disability who chose unassisted whom to live with ranged from 0% (nursing facility) to 8.6% (apartment).

Conclusions

Own Home

- People living in their own home (a home they own or rent themselves) had the **most choice**, followed by those living in an agency-operated apartment.
- Own home and agency operated apartment both show sharp changes in the percentage with choice by level of intellectual disability.

Group Home

- People living in group homes had **little choice**, as did institution residents.
- Group home provides much the same low amount of choice of living companions regardless of level of intellectual disability.

Conclusions

- Systematically less choice of both where and with whom to live as level of intellectual disability moved from mild to profound.
- This difference was more marked for choice of living companions than for choice of where to live.

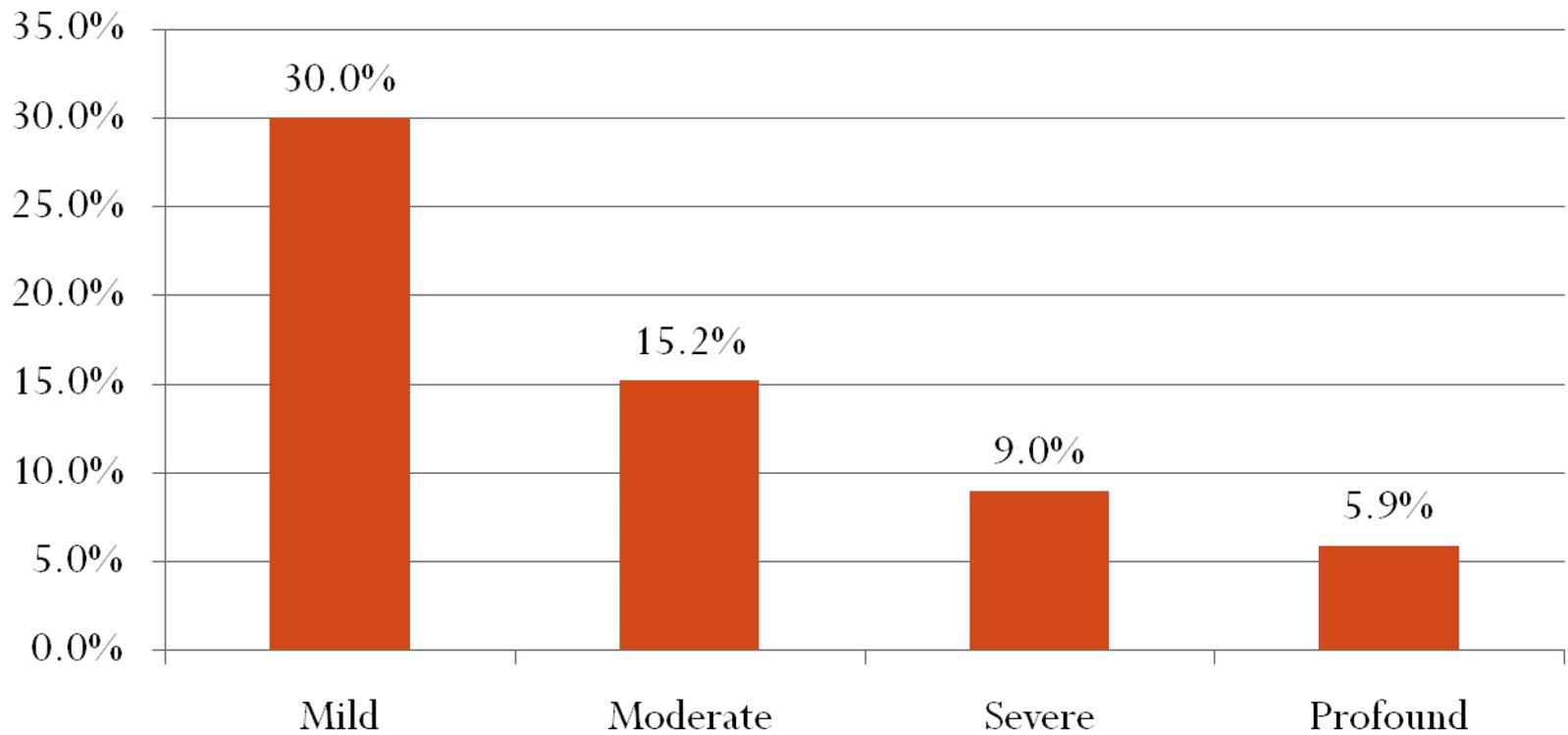


Residence Type and Level of Intellectual Disability

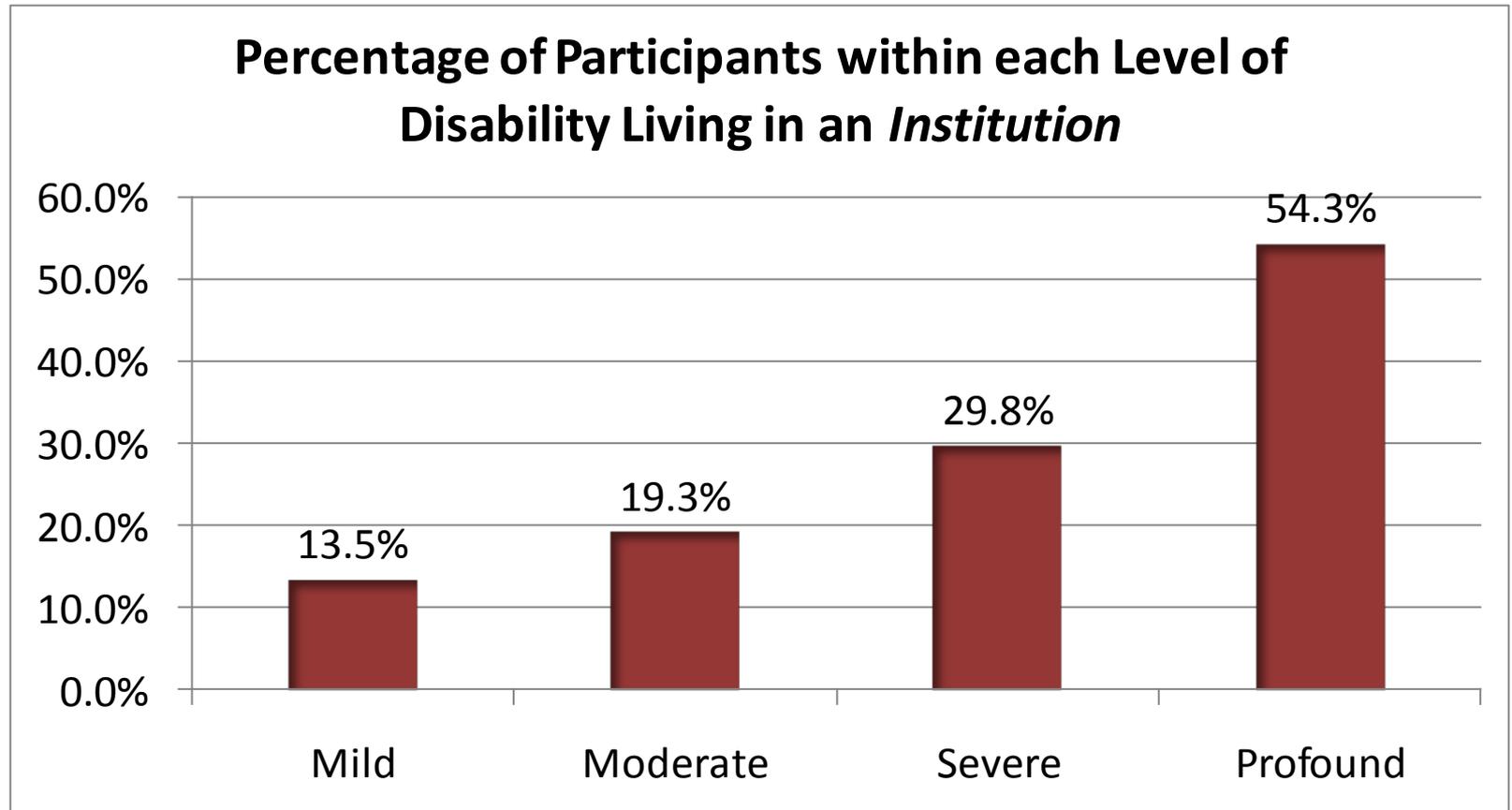
- Choice further limited for people with more severe disability due to the strong association between level of intellectual disability and residence type.
- People with more severe disability
 - experience less choice within a given residence type
 - have vastly less access to residence types associated with higher levels of choice, such as one's own home.

Own Home Residents by Level of Disability

Percentage of Participants within each Level of Disability Living in their *Own Home*



Institution Residents by Level of Disability



Conclusions

- The *majority* of adults with intellectual and developmental disabilities who lived in non-family-home settings did **not** chose where and with whom to live.
- Type of residential setting was also strongly related to these choices, with individuals living in their own home or an agency-operated apartment exercising the most choice.
- Individuals with severe or profound intellectual disability had little or no choice of where and with whom to live regardless of setting type.

Why are these choices important?

- People with disabilities have the **right** to choose where and with whom to live (UN Convention, 2006).
- People with disabilities clearly say they want to make these life-defining choices.
- Choosing where and with whom to live is linked to **increased satisfaction and wellbeing**.
 - *Self-report* data from 1559 adults from 6 US states on (see Stancliffe et al., 2009):
 - Loneliness
 - Feeling happy
 - Feeling afraid at home or in your neighborhood
 - Home staff nice & polite
 - Liking home

Choice of Living Companions

- **No difference** on:
 - Feeling afraid at home or in your neighborhood
- **Better results** for those with choice of living companions:
 - Loneliness
 - Feeling happy
 - Home staff nice & polite
 - Liking home

Choice of Where to Live

- **No difference** on:
 - Loneliness
 - Feeling afraid at home or in your neighborhood
- **Better results** for those with choice of where to live:
 - Feeling happy
 - Home staff nice & polite
 - Liking home

Conclusions

- Those who chose their living companions (or to live alone) and those who chose where to live reported consistently better well-being outcomes on the majority of indicators.

Results Summary

Item	Chose Who to Live with	Chose Where to Live
Loneliness	✓	
Feeling happy	✓	✓
Afraid at home		
Afraid in neighbourhood		
Home staff nice	✓	✓
Like home	✓	✓



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Reference:s

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- Stancliffe, R. J., Lakin, K. C., Taub, S., Chiri, G., & Byun, S. (2009). Satisfaction and sense of well-being among Medicaid ICF/MR and HCBS recipients in six states. *Intellectual and Developmental Disabilities*, 47(2), 63-83.