



# Whose Life is it Anyway? Supporting Adults Living with Their Families

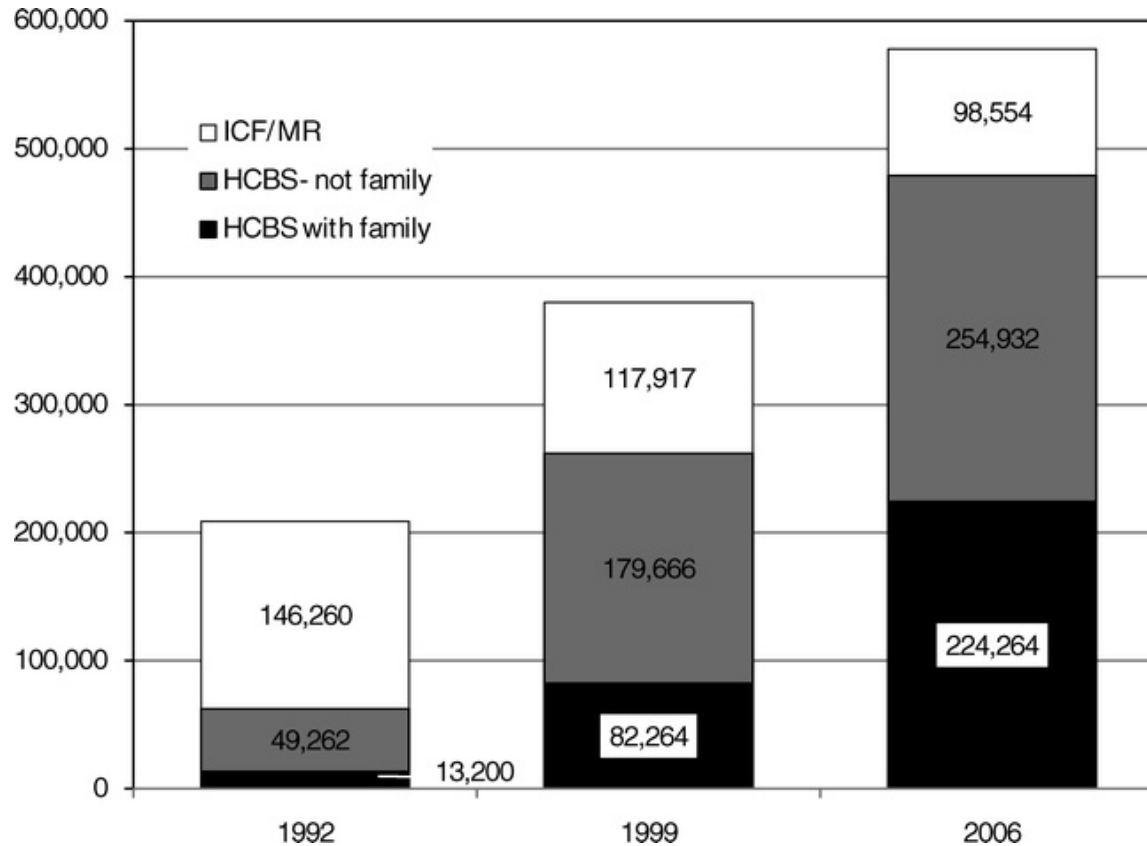
A Snapshot of Findings from National  
Core Indicators

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# What we know...most people with DD live at home with families

- 60% of 3.24 million people with developmental disabilities in the US live with family caregivers (Braddock et al 2001)
- Over half (an estimated 552,559) of people receiving DD services live with their families (Prouty et al 2007)
- Estimated 88,249 waiting for residential services (Prouty et al 2007)

# People receiving Medicaid services are increasingly likely to live at home



Proportion of HCBS recipients living with family increased from 6% to 22% to 39% (Lakin et al 2007)

# What can we learn from NCI?

- **Adult Consumer Survey** – adults 18 and over receiving at least one service besides case management – looked at results by residence
- **Adult Family Survey** – families with an adult family member living at home
- **Family Guardian Survey** – families and guardians of an adult living outside the home

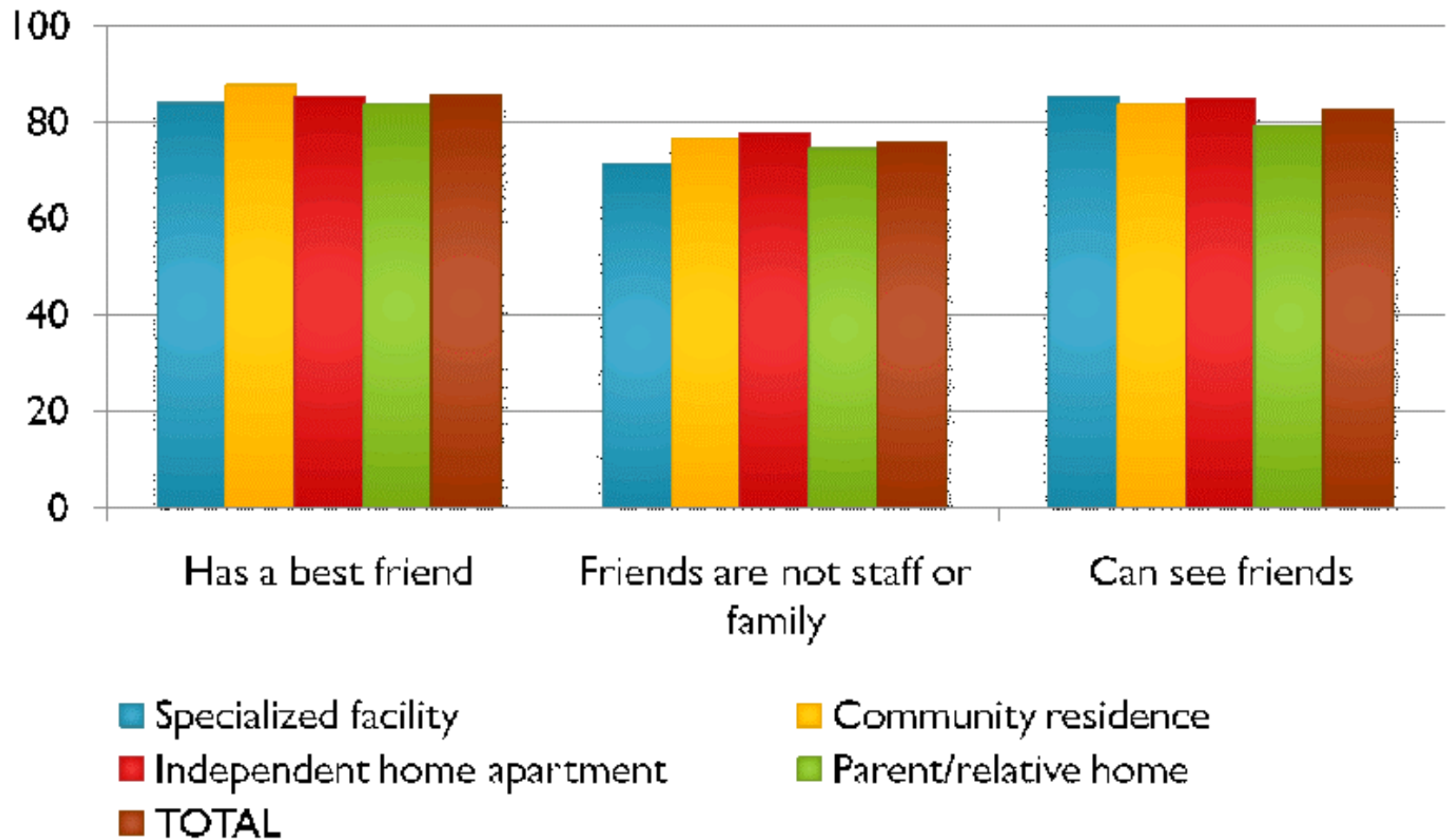
# NCI Adult Consumer Survey

- Data from 2006-2007
- 12,193 people interviewed across 19 states and one regional area
- Compared results across settings
  - ? Home of parent or other relative
  - ? Independent home or apartment
  - ? Community residence
  - ? Specialized facility

# Friendships

- Compared to adults in other residential settings, people living with family are:
  - ? least likely (about the same as people living in specialized facilities) to report having a best friend
  - ? most likely to report not having any friends
  - ? least likely to be able to see friends when they want to

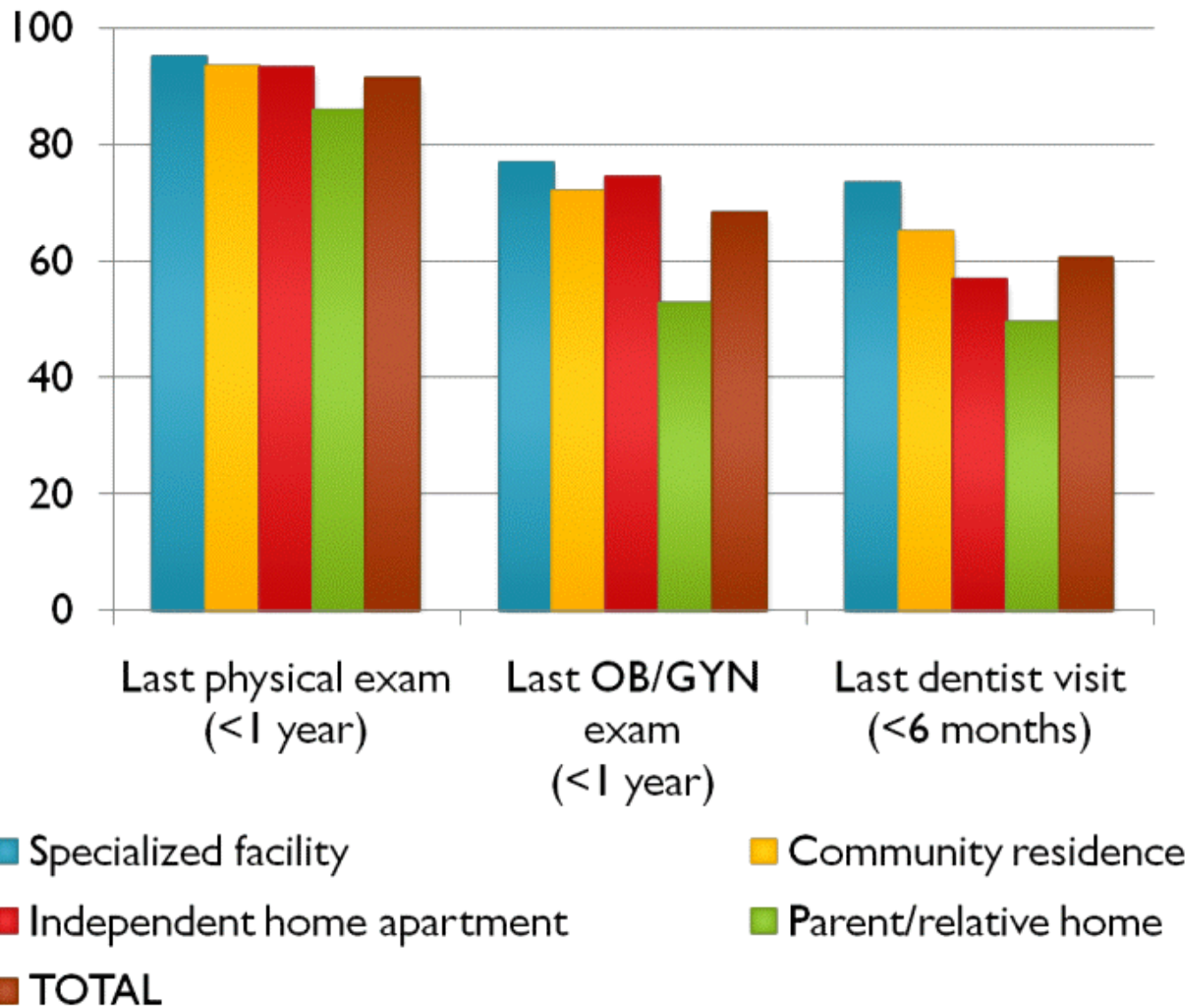
# Friendships



# Health

- Compared to adults in other residential settings, people living with family are:
  - ? least likely to have had a physical exam in the past year
  - ? least likely (women) to have had a GYN exam in the past year
  - ? least likely to have been to the dentist in the past 6 months

# Health

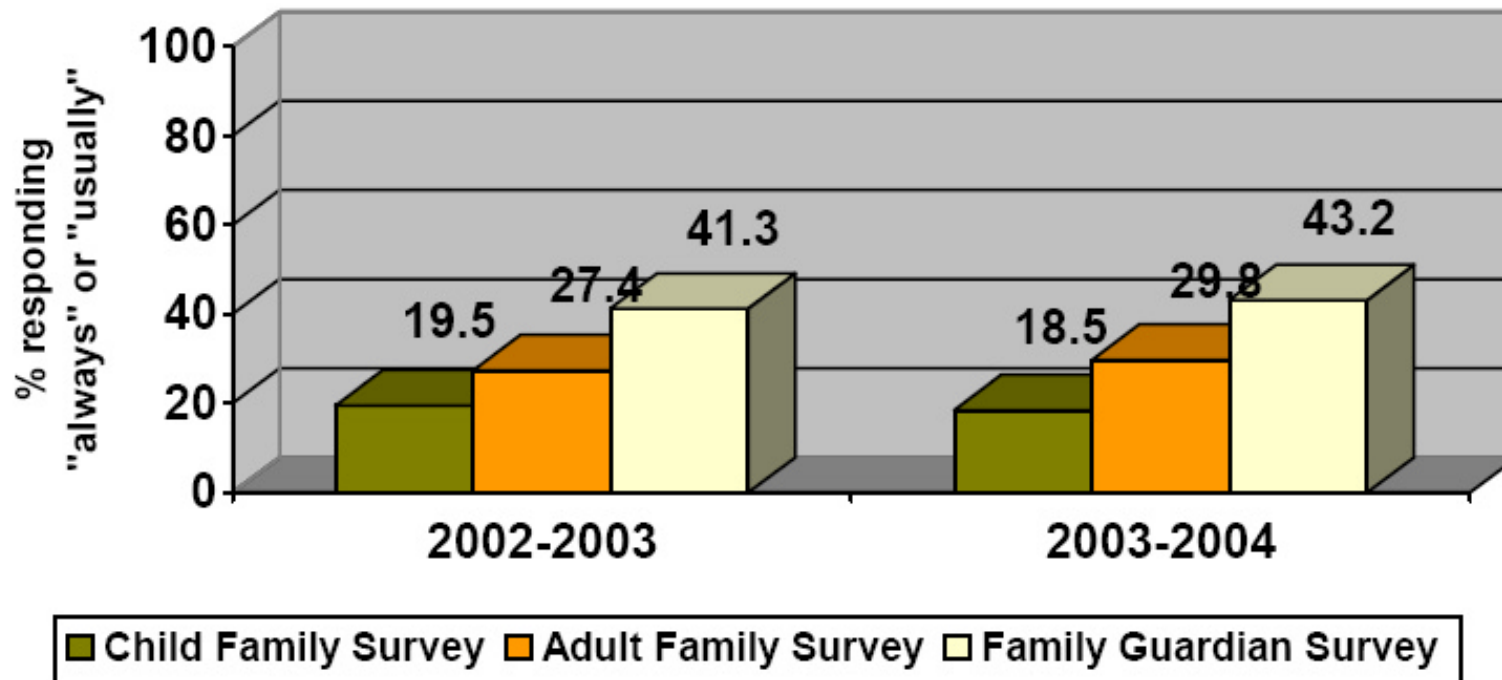


# Comparison of NCI Family Surveys: “In-home” vs. “Out-of-home”

- Families of people who live outside the home were more satisfied with planning and delivery of services, although having less involvement and control.
- Families with a family member living at home felt more isolated and cut off from their communities. (Bradley & Moseley 2007)

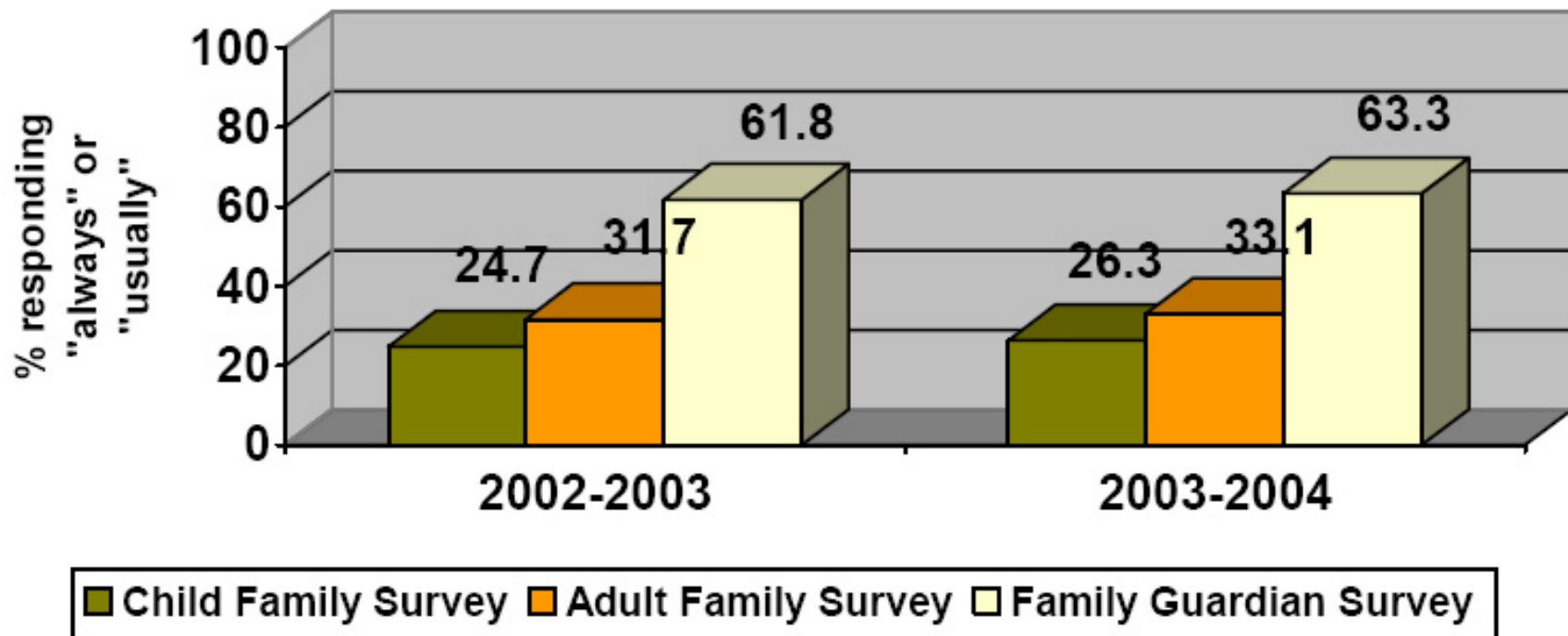
# Families with a family member living at home reported less community participation...

**CHART 15: Does your family member participate in community activities?**



...and less support to connect to community resources

**CHART 16: If you want to use typical supports in your community, do either the staff who help you plan or who provide support help connect you to these supports?**



# Families envision fuller lives for their adult children living at home...

- *“I am somewhat satisfied with support services, in regards to work and support my child receives there. However, I feel there is not much information on availability of social activities for adults with disabilities. I feel my child is pretty much cut off from social activities and meeting new people.”*
- *“As I begin to explore services for my adult family member, I am learning about the inadequacy of choices, especially social and educational, for a person over twenty-one with a developmental disability. We seem to focus so much on work and neglect the other aspects important to leading a full and satisfying life.”*



# For More Information on NCI

- [www.nationalcoreindicators.org](http://www.nationalcoreindicators.org)
- Email: [staub@hsri.org](mailto:staub@hsri.org)

# References

- Bradley, V. J., & Moseley, C. (2007). National core indicators: Ten years of collaborative performance measurement. *Intellectual and Developmental Disabilities, 45*, 354-58.
- Braddock, D., Emerson, E., Felce, D., & Stancliffe, R. J. (2001). Living circumstances of children and adults with mental retardation or developmental disabilities in the United States, Canada, England and Wales, and Australia. *Mental Retardation and Developmental Disabilities Research Reviews, 7*, 115-121.
- Lakin, K. C., Prouty, R., & Coucouvanis, K. (2007). HCBS recipients are increasingly likely to live with parents or other relatives. *Intellectual and Developmental Disabilities, 45*, 359-361.
- Prouty, R. W., Alba, K., & Lakin, K. C. (2007). *Residential services for persons with developmental disabilities: Status and trends through 2007*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.