



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

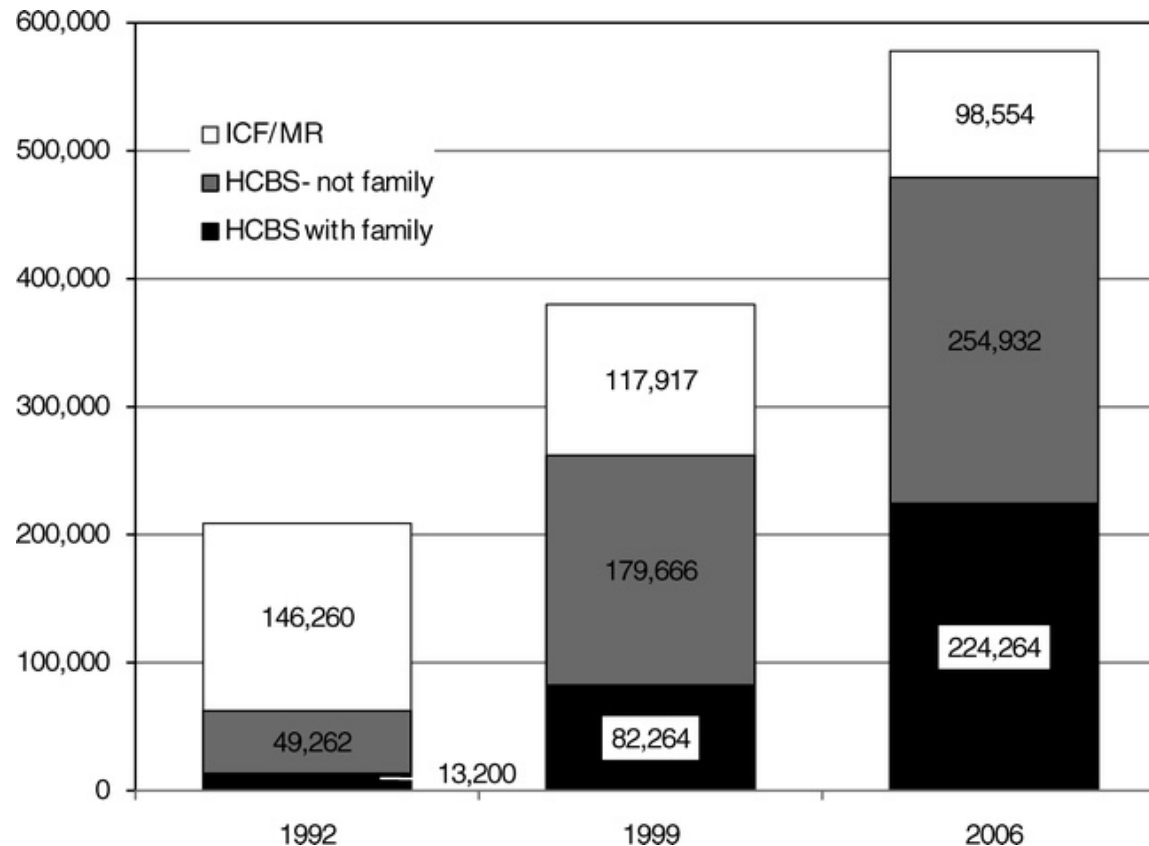
A Snapshot of Findings from National
Core Indicators

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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

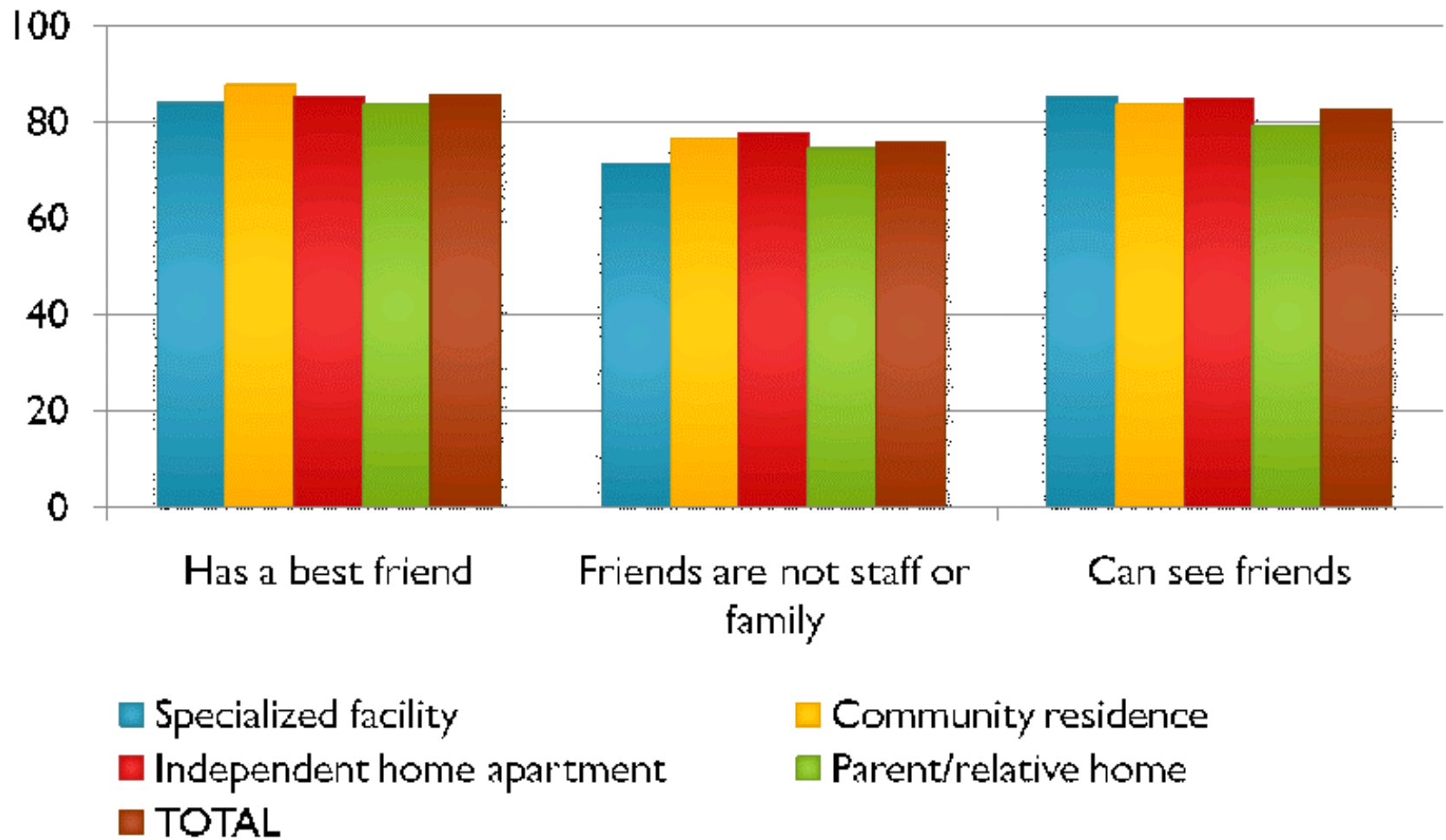
NCI Adult Consumer Survey

- 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

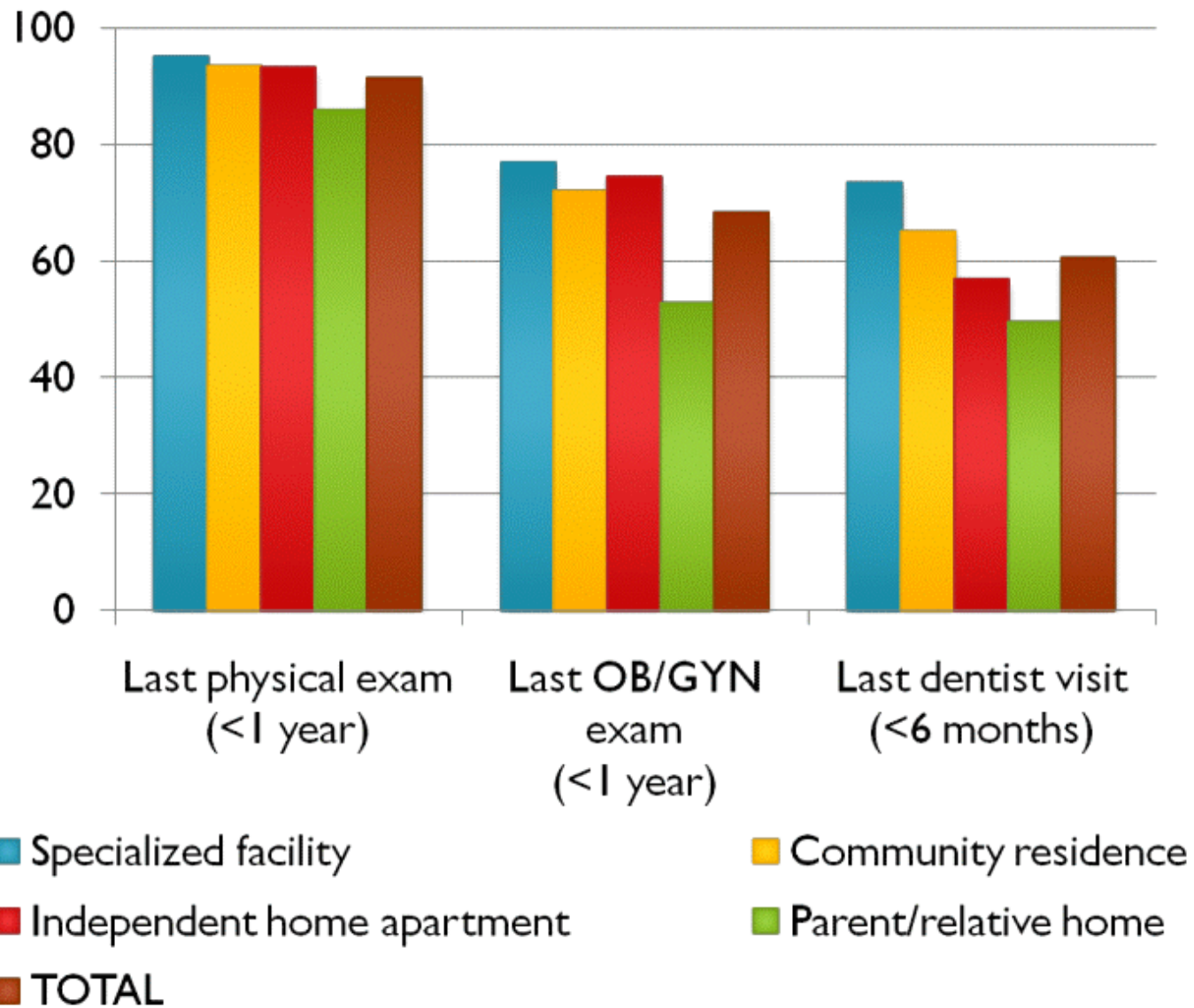
Friendships



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

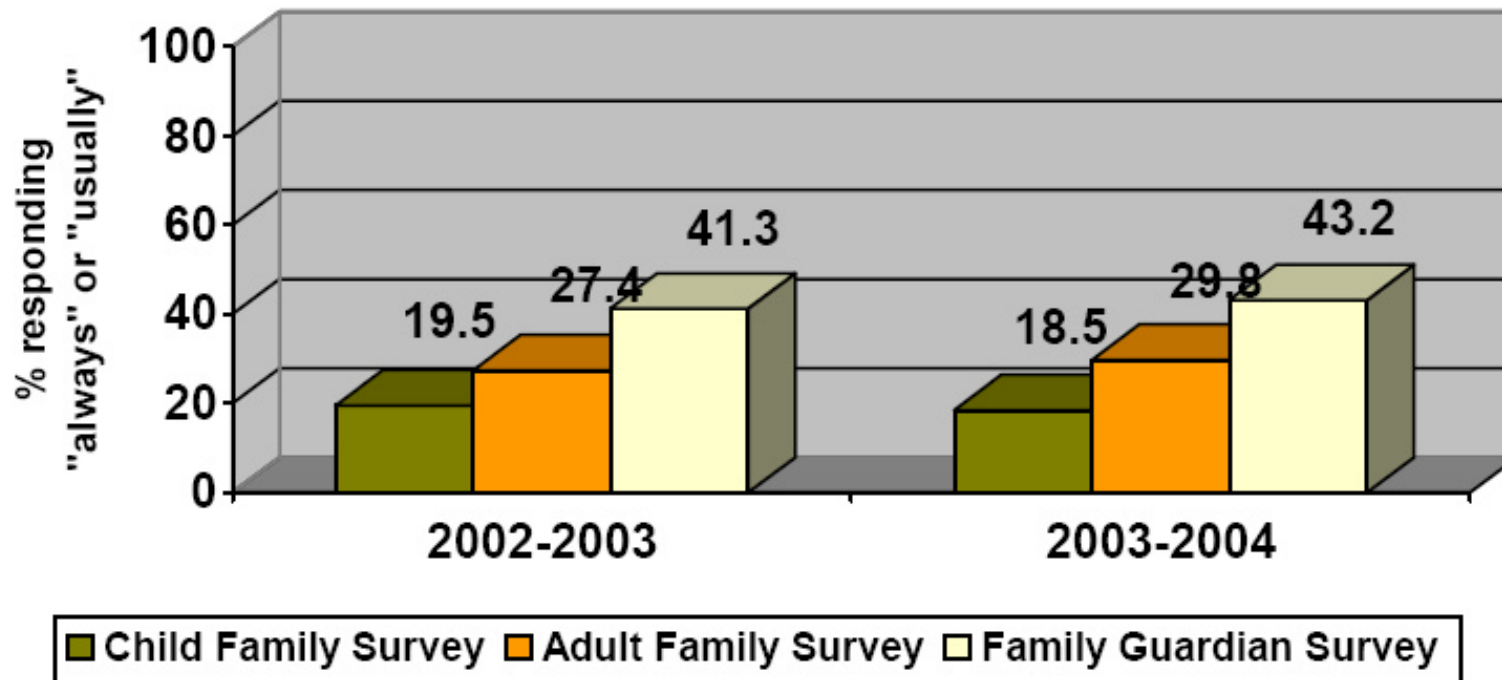


Comparison of NCI Family Surveys: “In-home” vs. “Out-of-home”

- 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)

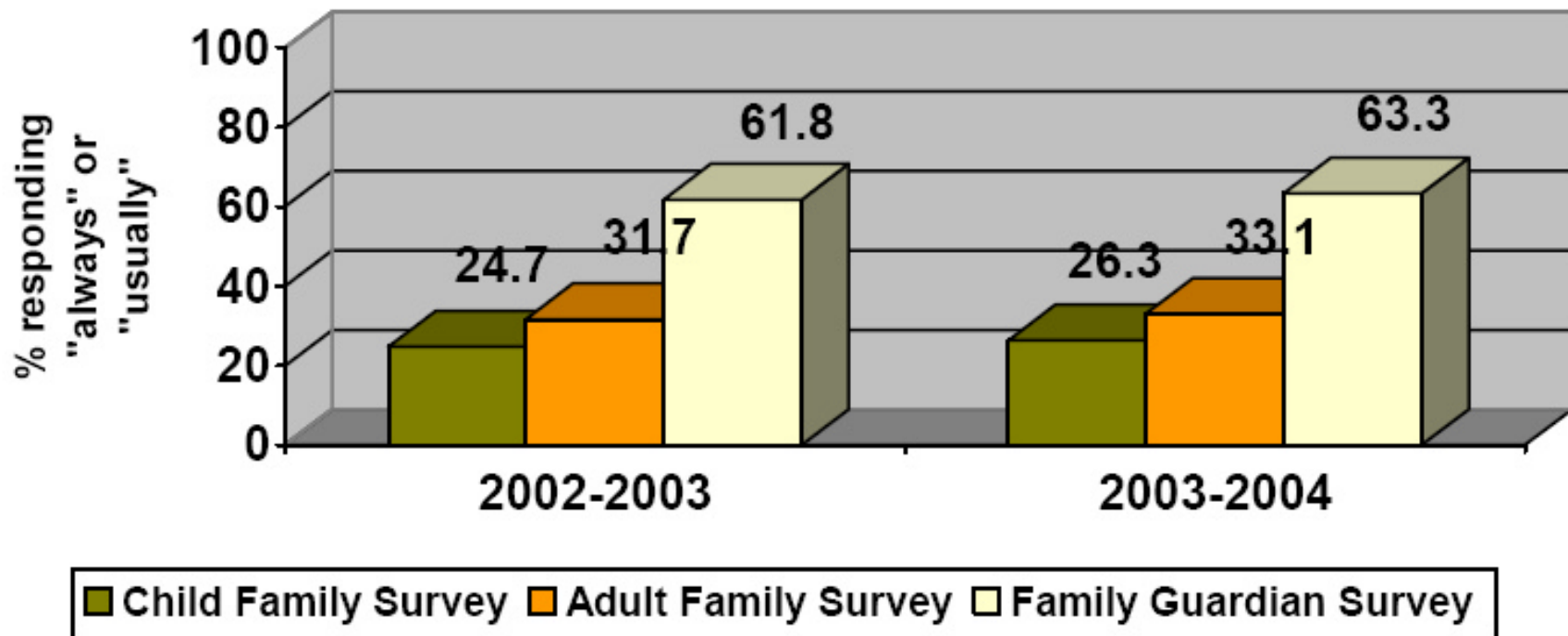
Families with a family member living at home reported less community participation...

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
- Email: 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.