

Outcomes in Self-Determination, Well-Being, Services Access and Expenditures: Findings from the Experiences of 3,000 HCBS and ICF/MR Recipients from Six States

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Complete report may be downloaded at:
<http://rtc.umn.edu/docs/HCBSFinalrprt.pdf>



What Is NCI?

- Nationally recognized set of performance and outcome indicators for developmental disabilities service systems
- Reliable data collection methods & tools
- Baseline and trend data at the state & national level
- Benchmarks of performance



NCI History

- Co-sponsored by NASDDDS and HSRI
- Launched in 1997
- Formed steering committee (including seven field test states)
- Compiled ~60 candidate performance indicators
- Developed and tested data collection instruments
- 24 states currently participating



Context of the Study

- Increasing number of people receiving HCBS services and supports
- Decline in numbers of individuals receiving services in ICFs/MR
- Increasing emphasis on self-determination and self-direction
- Focus on choice
- Concerns about differential outcomes by setting and associated with individual characteristics



Study Background

- Research funded by the Centers for Medicare and Medicaid Services (CMS) through a contract between CMS and the Lewin Group, and subcontracts between the Lewin Group and the University of Minnesota, MEDSTAT/Thomas, and the Human Services Research Institute (HSRI)



Study Background

- This study examined the outcomes of efforts in six selected states
- It is part of a larger evaluation of Medicaid Home and Community-Based Services whose purpose is to study of the impact of Medicaid Home and Community-Based Services programs on quality of life, quality of support, service utilization and cost

Questions

- 1) How Medicaid HCBS program funds are currently used?
- 2) How programs and policies affect costs, access to needed support and quality of services?
- 3) How program design features may be associated with cost-effective use of program options?



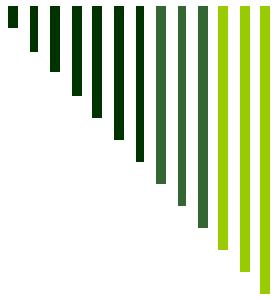
Study Background

- Study is based on ~3,000 Medicaid HCBS and ICF/MR recipients in Alabama, Kentucky, Indiana, Oklahoma, Massachusetts and Wyoming
- Uses the NCI consumer survey
- Linked with Medicaid cost data
- Total consumer interviews in six states: 3,255 (all service recipients)
- Total HCBS and ICF/MR interviews: 2,948 (90.6%)



Individual Outcomes Assessment

- The National Core Indicators (NCI) program was developed through a partnership of the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI)
- NCI data gathered with a common instrumentation package
 - Meets accepted standards as being both valid and reliable.
- Standard training program for interviewers



Selected Characteristics of Adults (18 and Older) with ID/DD Receiving Medicaid HCBS and ICF/MR Services in Six States

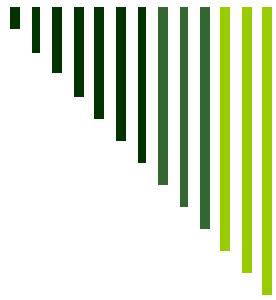
HCBS		ICF/MR	
Gender			
Male	56.9%	Male	57.3%
Female	43.1%	Female	42.7%
Age¹			
Average Age	42.25	Average Age	45.38

¹ Sig. t=-5.227 p<.001



Criteria for Selecting States for Participation

- States with samples drawn randomly from institutional and community services
- Regional variation
- Both urban and rural states
- Demographic variety
- Variation in mix of institutional and community services



“Representativeness” of Six State Sample

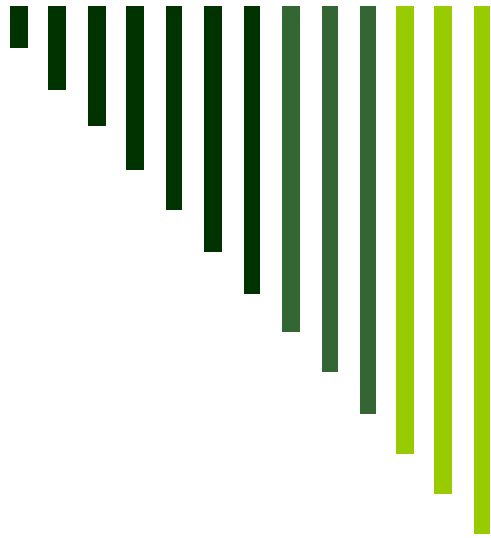
<u>Group</u>	<u>HCBS</u>		<u>ICF/MR</u>	
	Number	%	Number	%
U.S.A. (June 2004)*	424,855	80.2%	104,526	19.8%
Six States (June 2004)	33,875	80.1%	8,391	19.9%
Sample (2003-2004)	2,365	80.2%	583	19.8%

*U.S.A. and 6 state totals include children and adults; sample included only adults (18 years and older)



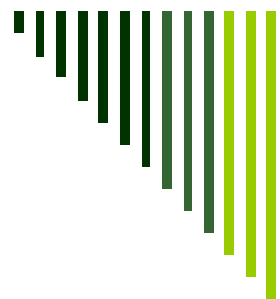
Four Major Analyses

- 1. Access to Community Settings, Resources, and Opportunities for Persons with Intellectual and Developmental Disabilities with Different Degrees and Types of Disability***
 - 2. “Self-Determination Among Medicaid Home and Community-Based Services (HCBS) and ICF/MR Recipients in Six States”***
 - 3. “Satisfaction and Sense of Well-Being Among Medicaid ICF/MR and HCBS Recipients in Six States”,***
 - 4. “Loneliness and Living Arrangements”***
 - 5. “Factors Associated with Expenditures for Medicaid Home and Community Based Services and ICF/MR Services for Persons with Intellectual and Developmental Disabilities in Four States”***
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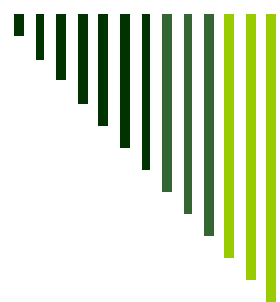
Study #1

“Access to Community Settings, Resources, and Opportunities for Persons with Intellectual and Developmental Disabilities with Different Degrees and Types of Disability”



Focus of Study #1

- Access to community settings
- Resources and opportunities for persons with intellectual and developmental disabilities with different degrees and types of disabilities



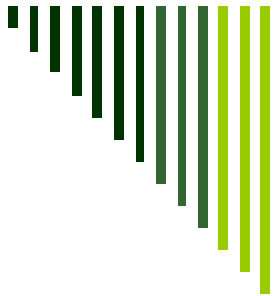
Profile of HCBS and ICF/MR Recipients

□ HCBS

- Mild level of ID (43%)
- No seizure disorder (73%)
- Verbal (81%)
- Ambulatory (89%)

□ ICF/MR

- Mild level of ID (27%)
- No seizure disorder (66%)
- Verbal (67%)
- Ambulatory (80%)



Selected Characteristics of Adults (18 and Older) with ID/DD Receiving Medicaid HCBS and ICF/MR Services in Six States

HCBS		ICF/MR	
Level of ID ²			
Mild	40.6%	Mild	25.6%
Moderate	25.7%	Moderate	14.9%
Severe	15.0%	Severe	18.9%
Profound	14.2%	Profound	38.0%
None	2.0%	None	0.7%
(Not Reported)	2.5%	(Not Reported)	1.9%

² Sig. $\chi^2=199.916$ $p<.001$

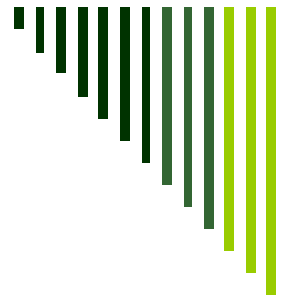


Selected Characteristics of Adults (18 and Older) with ID/DD Receiving Medicaid HCBS and ICF/MR Services in Six States

HCBS		ICF/MR	
Psychiatric Diagnosis			
% No	69.4	% No	66.7
% Yes	30.6	% Yes	33.3
Autism			
% No	93.8	% No	93.8
% Yes	6.2	% Yes	6.2
Cerebral Palsy³			
% No	86.0	% No	81.9
% Yes	14.0	% Yes	18.1
Seizure or Neurological Disorder⁴			
% No	33.0	% No	41.9
% Yes	10.0	% Yes	9.0

³ Sig. $\chi^2=6.056$ $p<.05$

⁴ Sig. $\chi^2=15.78$ $p<..001$



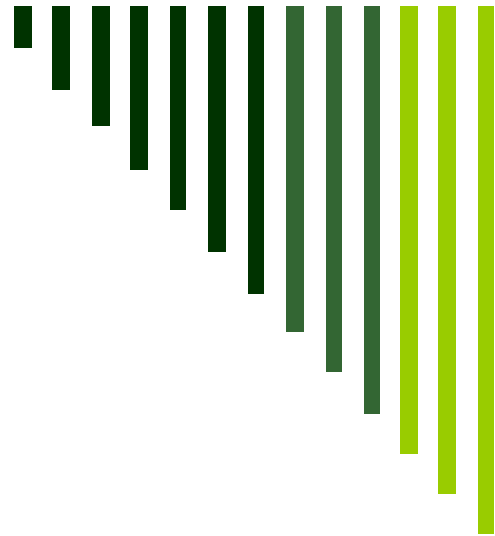
Residential Settings of People with Different Levels and Types of Disability

- People with more severe disability and with additional disabilities live in larger settings
- Type of disability has a differential impact on where a person will reside



Policy Implications

- Waiver supports need to be expanded to accommodate people regardless of the level and nature of their disabilities
- We need to redouble our efforts to help people in large ICF/MR facilities to move to community settings
- Findings emphasize that people can be served in community settings rather than initially being placed in large facilities



Study #2

***“Self-Determination Among
Medicaid Home and Community-
Based Services (HCBS) and
ICF/MR Recipients in Six States”***



Focus of Study #2

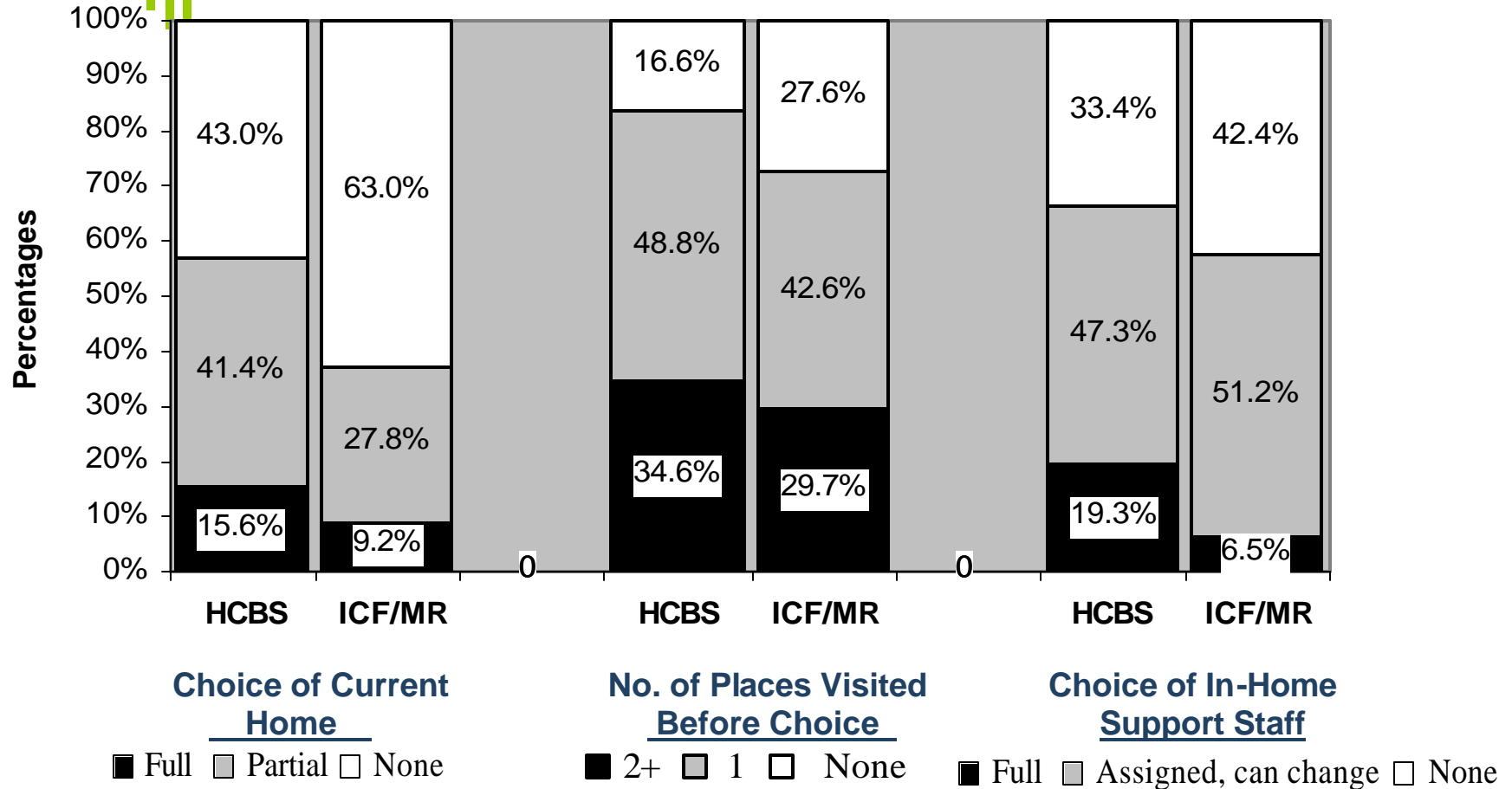
- Self-determination in the lives of persons with intellectual and developmental disabilities (ID/DD) receiving Medicaid Home and Community Based Services (HCBS) and Intermediate Care Facility (ICF/MR) services



Choice in Daily Life

- HCBS recipients
 - 16% chose home on their own
 - 19% chose home staff
 - 54% autonomously determines use of spending money
 - 64% decide on their own use of spare time
 - 53% control daily schedule
- ICF/MR recipient
 - 9% chose home on their own
 - 6.5% chose home staff
 - 39% autonomously determines use of spending money
 - 43% decide on their own use of spare time
 - 26% control daily schedule

Chart 16. Reported Opportunities for Choice in Housing Among HCBS and ICF/MR Recipients in Six States





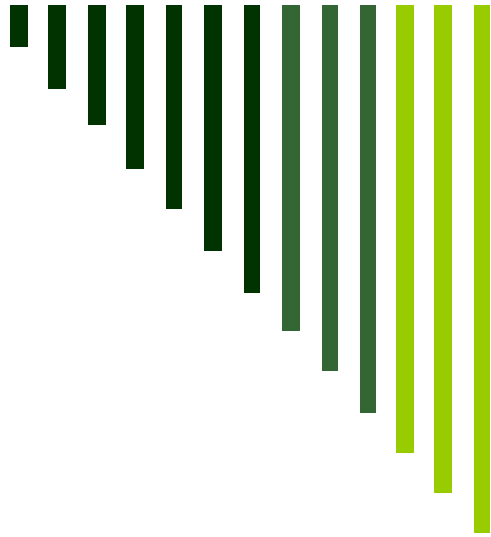
Additional Findings

- Individual characteristics, HCBS vs. ICF/MR program participation and size of residential setting consistently associated with self-determination
- More severe levels of ID or co-occurring conditions associated with less choice and control
- Verbal ability also strongly linked with choice-making abilities
- Effects more noticeable for ICF/MR service recipients



Policy Implications

- Choice should be present in the lives of individuals regardless of where they live
- For those who live in large structured settings, we need to alter our expectations insofar as standards and monitoring in order to ensure that such individuals experience choice



Study #3: Satisfaction and Sense of Well-Being

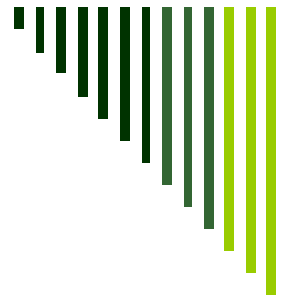
Roger J. Stancliffe¹, K. Charlie Lakin¹,
Sarah Taub², Robert Doljanac¹,
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 2. Human Services Research Institute
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Self-Report Data Only

- Satisfaction and well-being items come from **Section I** of the NCI Consumer Survey.
- This may *only* be completed by interviewing the person receiving services. Due to communication difficulties, some service users could not take part in the interview.
- Only included HCBS and ICF/MR recipients who were judged by interviewers to have given **valid** and **consistent** interview responses.
- These selection criteria yielded a total of 1885 individuals - predominantly of people with mild or moderate ID.



Satisfaction and Well-being Outcomes

- Loneliness
- Feeling happy

At Home

- Feeling afraid at home
- Feeling afraid in your neighborhood
- Home staff nice & polite
- Liking home

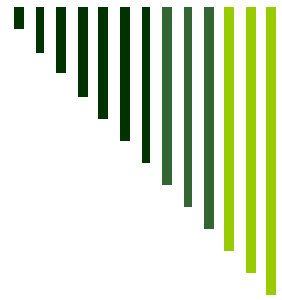
Work/Day Program

- Work staff nice & polite
- Liking work/day program



Relation with Personal Characteristics

- Well-being and satisfaction outcomes were consistently correlated with the presence of a ***psychiatric diagnosis***.
- People with a psychiatric diagnosis may be particularly vulnerable to poorer satisfaction and sense of well-being.



Subjective well-being

- People adapt to circumstances, even unfavorable circumstances, and their self-reported satisfaction and sense of well-being remains reasonably stable over time.
- Such *subjective* outcomes tend to have little or no relation to objective outcomes or to objective features and quality of service provision (Cummins, 2001; Perry & Felce, 2005).
- Not clear at the beginning this research whether the satisfaction and sense of well-being data would be sensitive to differences across programs and service settings.



Concrete, simple questions

- Questions about abstract concepts such as “satisfaction with services” are difficult for people with ID/DD to understand and respond to.
- Rather than using abstract, global questions, the NCI protocol captures “satisfaction” by using concrete concepts and simple words that are readily recognized by people with ID/DD:
 - *Are staff nice to you?*
 - *Are you ever afraid or scared when you are at home?*



HCBS:ICF/MR Comparisons

- No significant difference between HCBS & ICF/MR samples on:

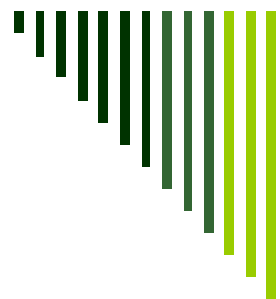
- Loneliness
- Feeling happy

At Home

- Feeling afraid at home
- Feeling afraid in your neighborhood

Work/day program

- Liking work/day program



Significant difference between HCBS & ICF/MR

Favoring HCBS

- Work staff nice & polite
- Liking home

Although significant, the differences were small.

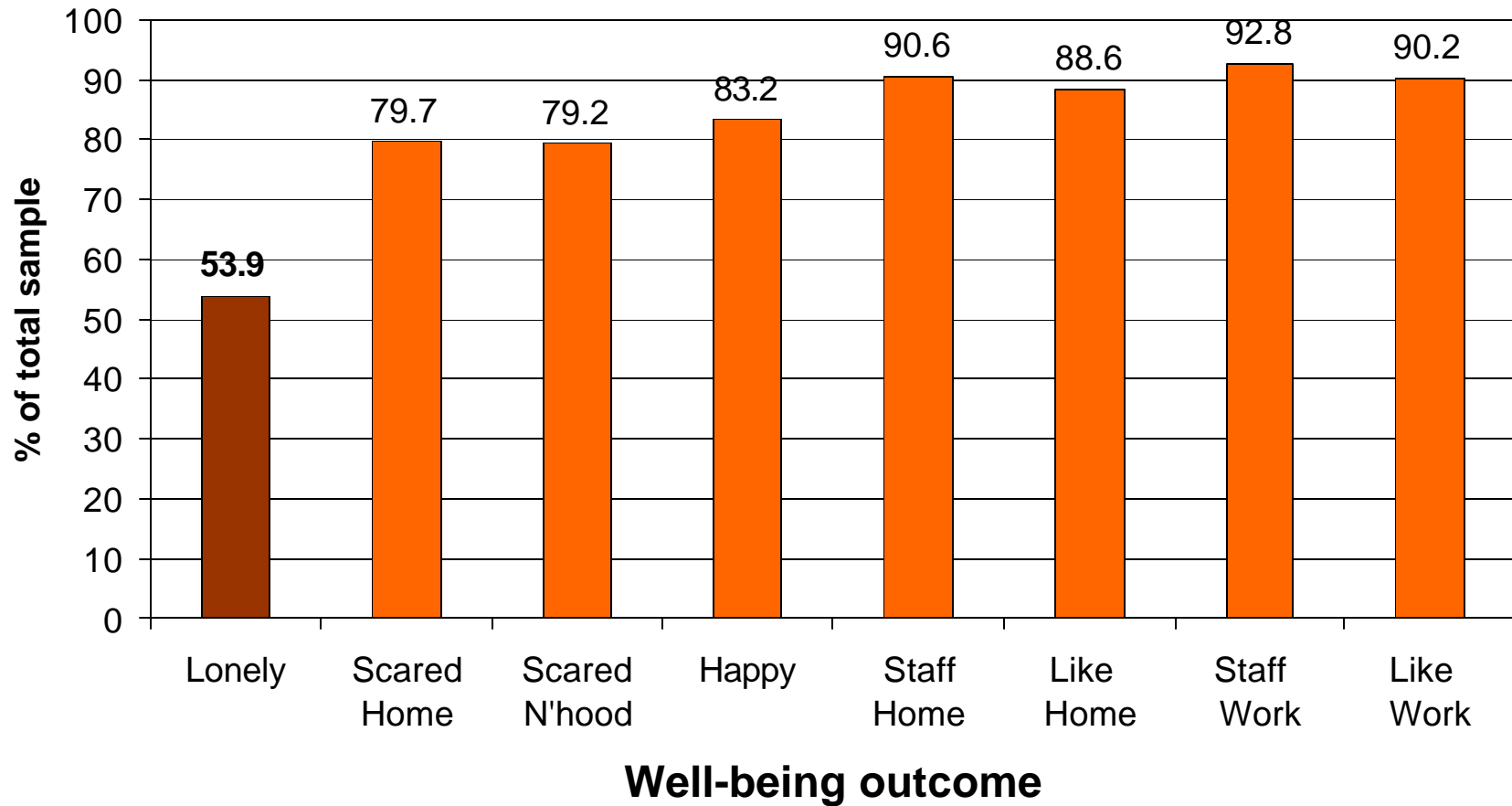
Favoring ICF/MR

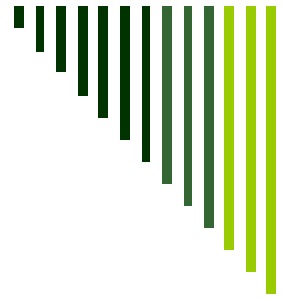
- Home staff nice & polite

Although significant, the differences were small.

Loneliness the most widespread problem

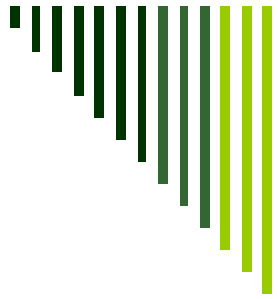
Percent with positive outcome





Conclusion

- Loneliness is a widespread problem requiring sustained attention.

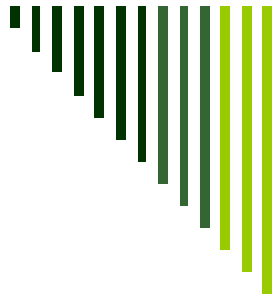


Comparisons by Residence Size

(5 states – residence size data not available for 1 state)

□ Contrasted satisfaction and well-being outcomes by residence size:

- 1 resident with ID/DD
- 2-3
- 4-6
- 7+



Comparisons by Residence Size

- No significant difference by residence size on:
 - Feeling afraid at home
 - Feeling afraid in your neighborhood
 - Feeling happy
 - Home staff polite

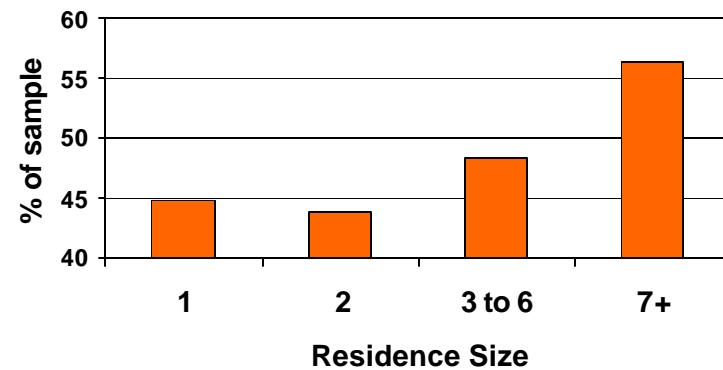
Work/day program items not analyzed as logically residence size is unrelated to these items.

Comparisons by Residence Size

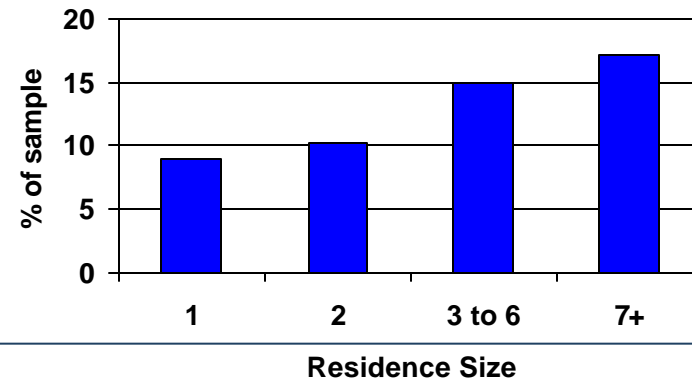
□ Better results in *smaller* residences for:

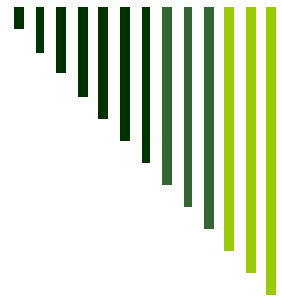
- Loneliness
- Liking home

% Lonely Sometimes or Often



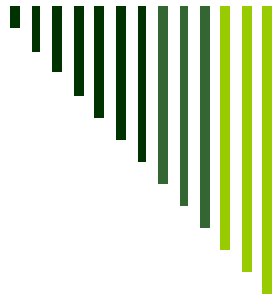
% Like Home? No or In-Between





Conclusion

- Findings provide further evidence to support the initiatives among the states to increase opportunities for persons with ID/DD to live in smaller, more individualized community homes.



Family vs. non-family residence

Work/day program items not analyzed as logically living arrangements are unrelated to these items.

- No difference on:
 - Feeling afraid in your neighborhood
- Better results for those NOT living with family on:
 - Home staff nice & polite
- Better results for those living with family on:
 - Loneliness
 - Feeling afraid at home
 - Feeling happy
 - Liking home



Conclusion

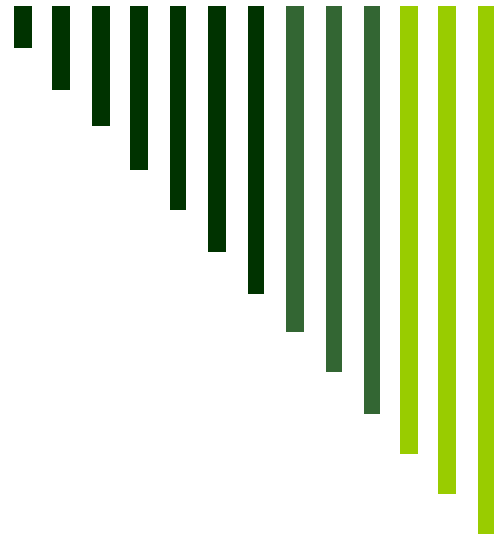
- These findings strongly support the growing trend to fund family-based services as a means of enabling people with ID/DD to remain living with their family.

- One possible explanation of lower satisfaction about paid staff in the family home is that, compared to family members who are constant in the person's life, individuals with ID/DD living with family may feel less comfortable with paid staff who come and go, and change over time.
 - This is consistent with the observed trend in consumer-directed family-support services toward hiring *familiar* people (family members, friends) to provide support.



Overall Conclusions

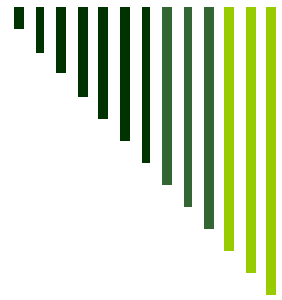
- Findings support the provision of residential services in very **small settings** and to individuals living **with family**.
- Careful attention needs to be given to reducing **loneliness**.
- People with a **psychiatric diagnosis** may be particularly vulnerable to poorer satisfaction and sense of well-being.



Study #4: Loneliness and Living Arrangements

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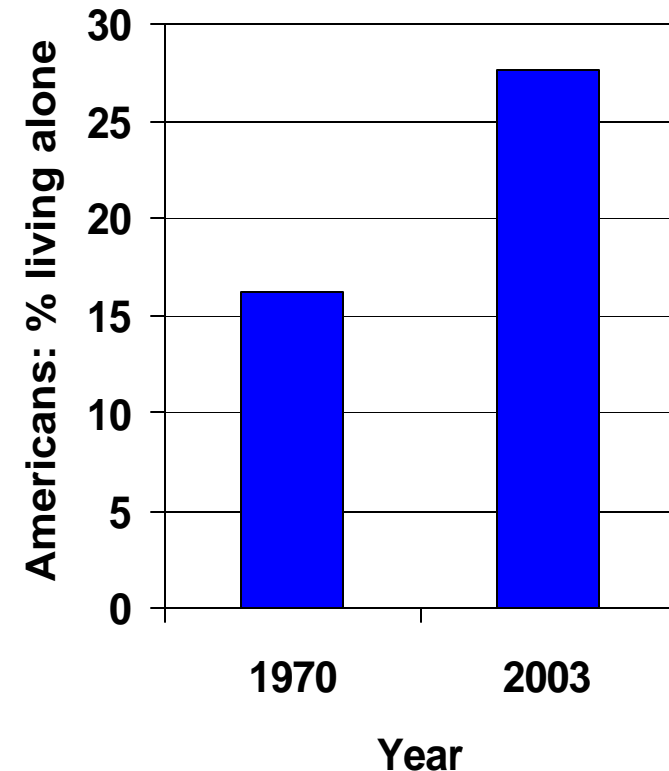
Why loneliness?

- When asked “*Do you ever feel lonely?*” substantial numbers of service users reported loneliness to be a problem.
- This study was intended to examine the relationship between community residence size and loneliness, with a particular focus on very small settings and living alone.



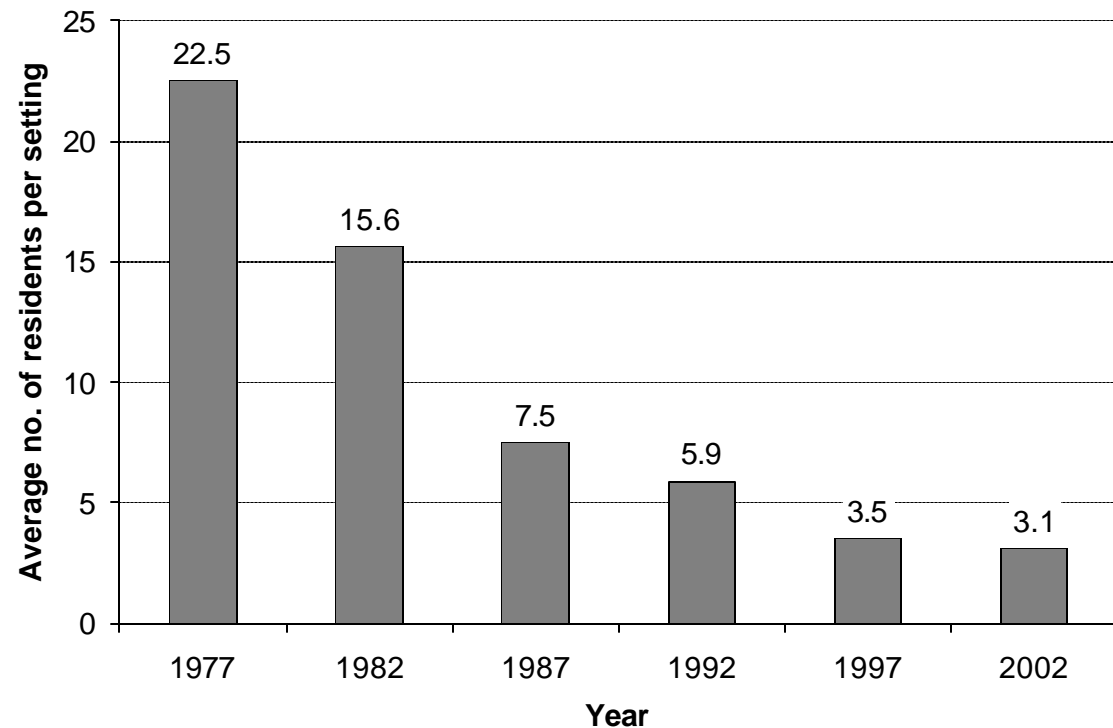
Percentage of Americans living alone 1970, 2003

- American households have decreased in size (Fields, 2004).
- More Americans now live alone (see chart).



Service Users with ID/DD

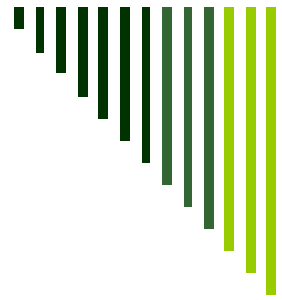
- Nationally in 2004, the average number of residents per setting was 2.8, with some 46% of service users living in households of 1 to 3 people (Coucouvani, Prouty, & Lakin, 2005)





Residence Size and Loneliness

- Adults with ID/DD live in increasingly small community settings where the risk of loneliness may be greater.
- People with ID/DD's social networks tend to be dominated by family, disability service staff (especially residential staff) and other service users (e.g., fellow residents).
- Living alone (or with one other person) could well reduce one's contact with fellow residents. Having part-time staff support reduces one's contact with staff.

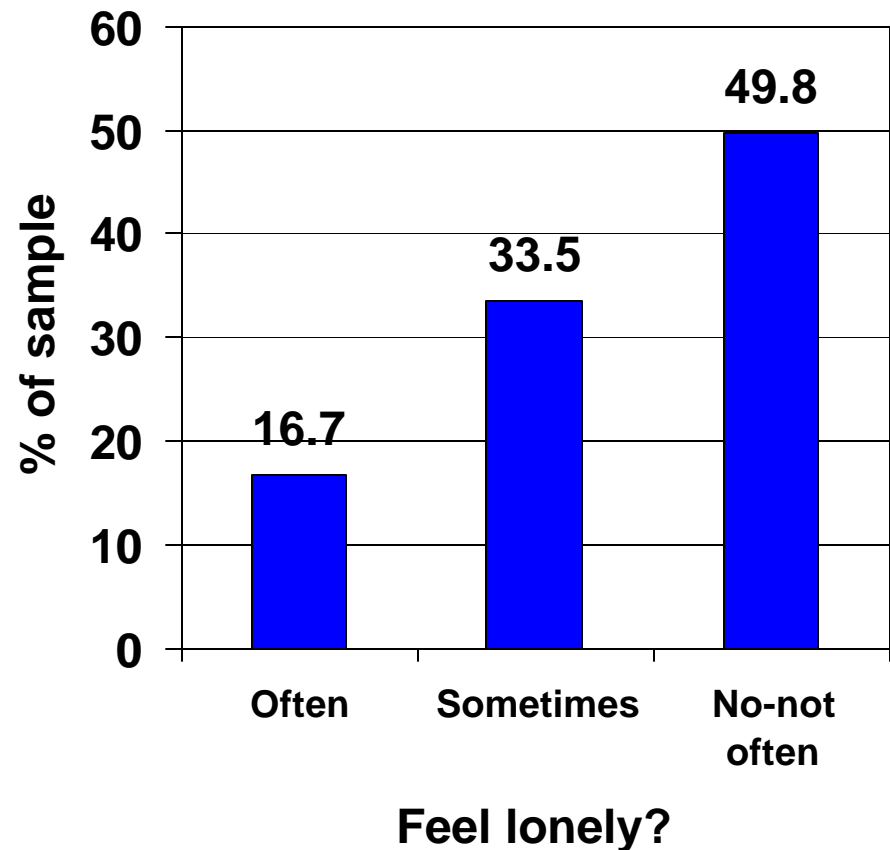


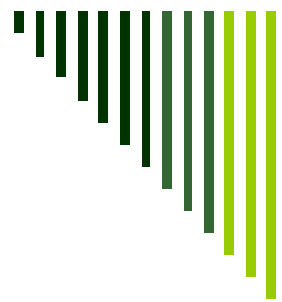
Procedure

- We examined self-reported loneliness among 1002 individuals with ID/DD from 5 states in relation to:
 - *community* residence size (i.e., settings with 1-15 people with ID/DD),
 - personal characteristics,
 - social contact,
 - social climate.

Loneliness Outcomes

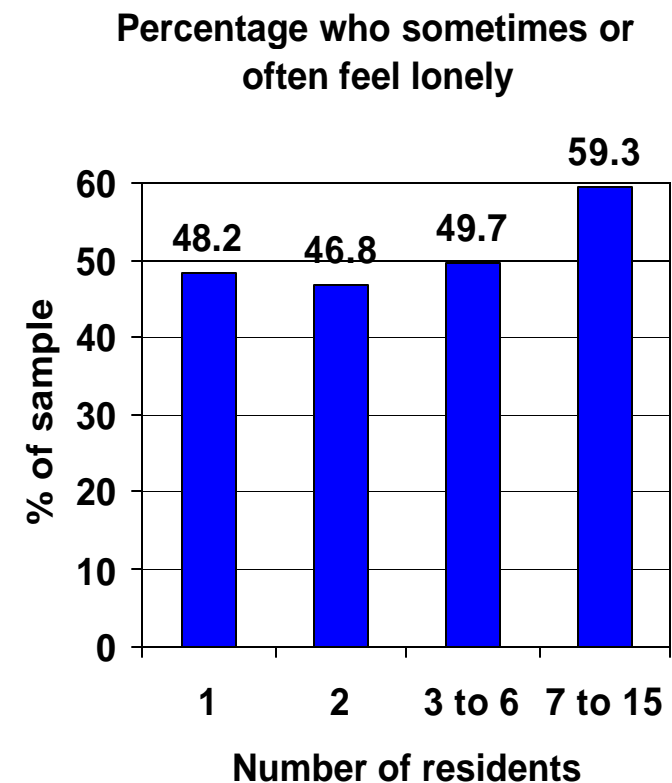
- One third reported being lonely *sometimes*.
- One sixth said they were *often lonely*.
- Sheppard-Jones et al. (2005) showed adults with ID/DD are significantly more lonely than the general adult population.





Loneliness and Residence Size

- Loneliness was **NOT** more common for people living alone or in very small settings.
- **No** difference between settings with 1 and with 2 residents.
- **No** difference between settings with 1-2 and 3-6 residents.
- Significantly **more** loneliness reported by residents of larger community living settings of 7-15 people than of 1-2 people ($p=.007$).





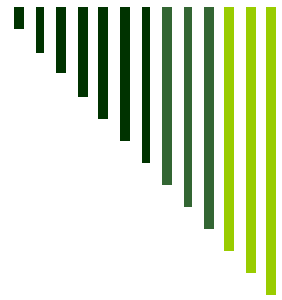
Multivariate analysis

- Differences by residence size remained significant even after differences in intellectual disability, challenging behavior, age and gender were controlled statistically.



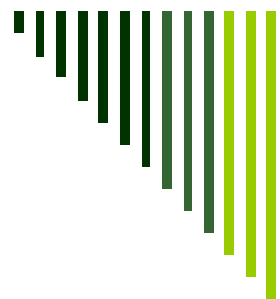
Conclusion

- Fears about greater loneliness when living alone are ill-founded and should not be used as a reason to prevent someone from living alone if they wish to.



Loneliness, Social Contact and Social Climate

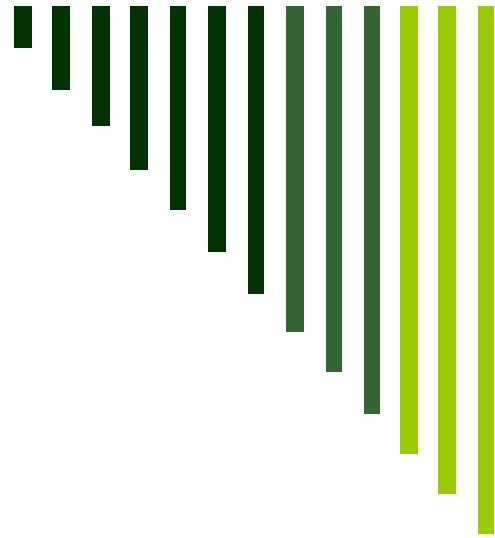
- More social contact with friends and with family, and liking where you live were significantly associated with **less** loneliness.
- Social climate variables such as being afraid at home or in one's local community were strongly associated with **more** loneliness.



Conclusion

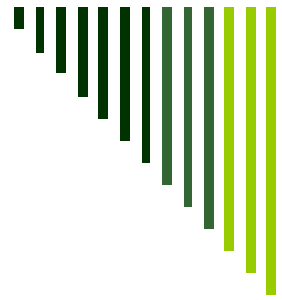
(Note: this cross-sectional study did not demonstrate cause and effect)

- Concerns about loneliness may be addressed by supporting the person to:
 - live in a safe neighborhood,
 - in smaller settings - alone or with compatible roommates,
 - to be free from fear at home, and
 - to have regular contact with friends and family.



Study #5

“Factors Associated with Expenditures for Medicaid Home and Community Based Services and ICF/MR Services for Persons with Intellectual and Developmental Disabilities in Four States”



Focus of Study #5

- Medicaid expenditures for persons with intellectual and developmental disabilities (ID/DD)
- Examined variations in expenditures for individuals of different characteristics and service needs

Chart 27. Est. Federal and State SS Act Expenditures for Adult HCBS and ICF/MR Recipients in Four States

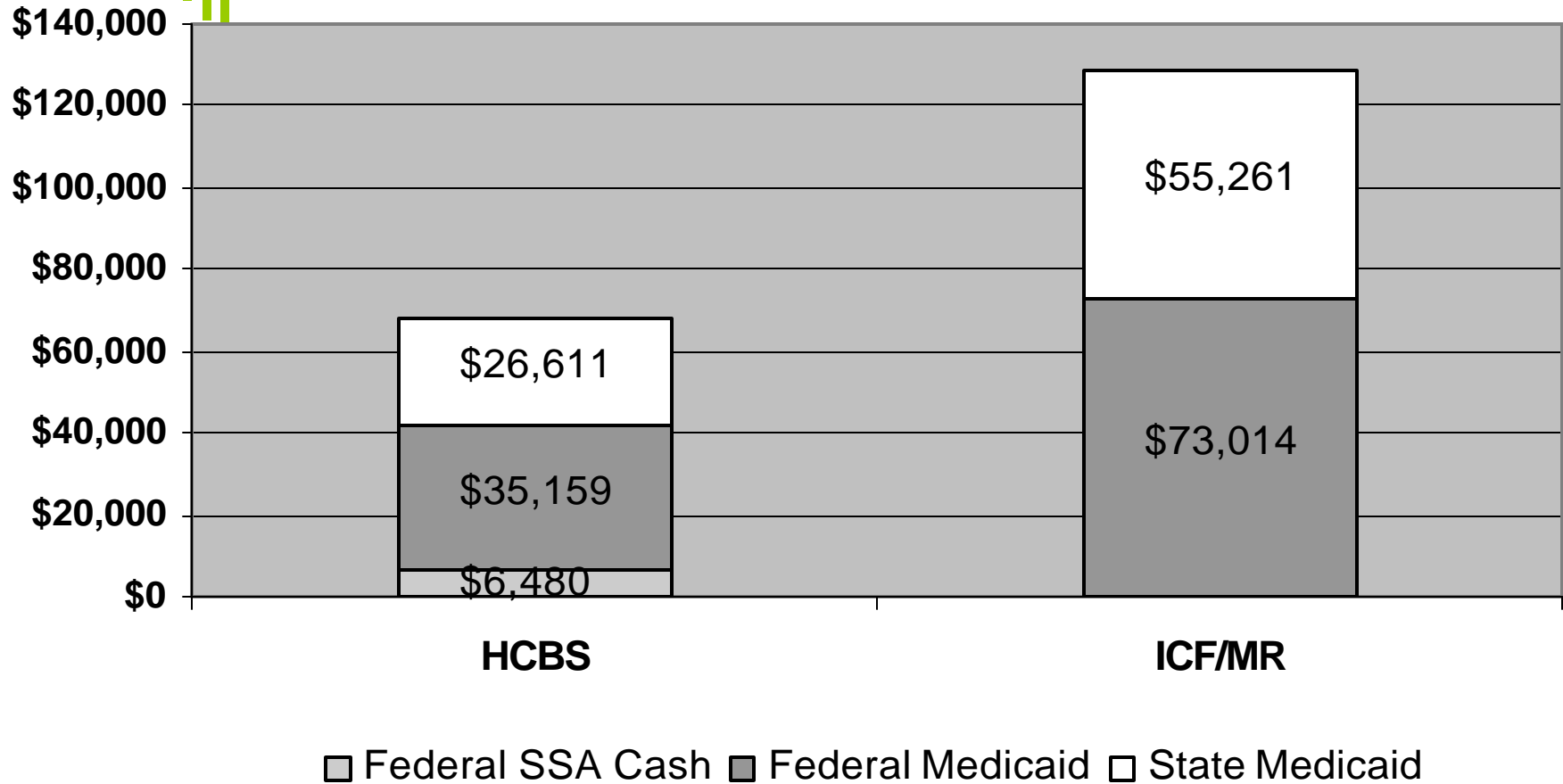
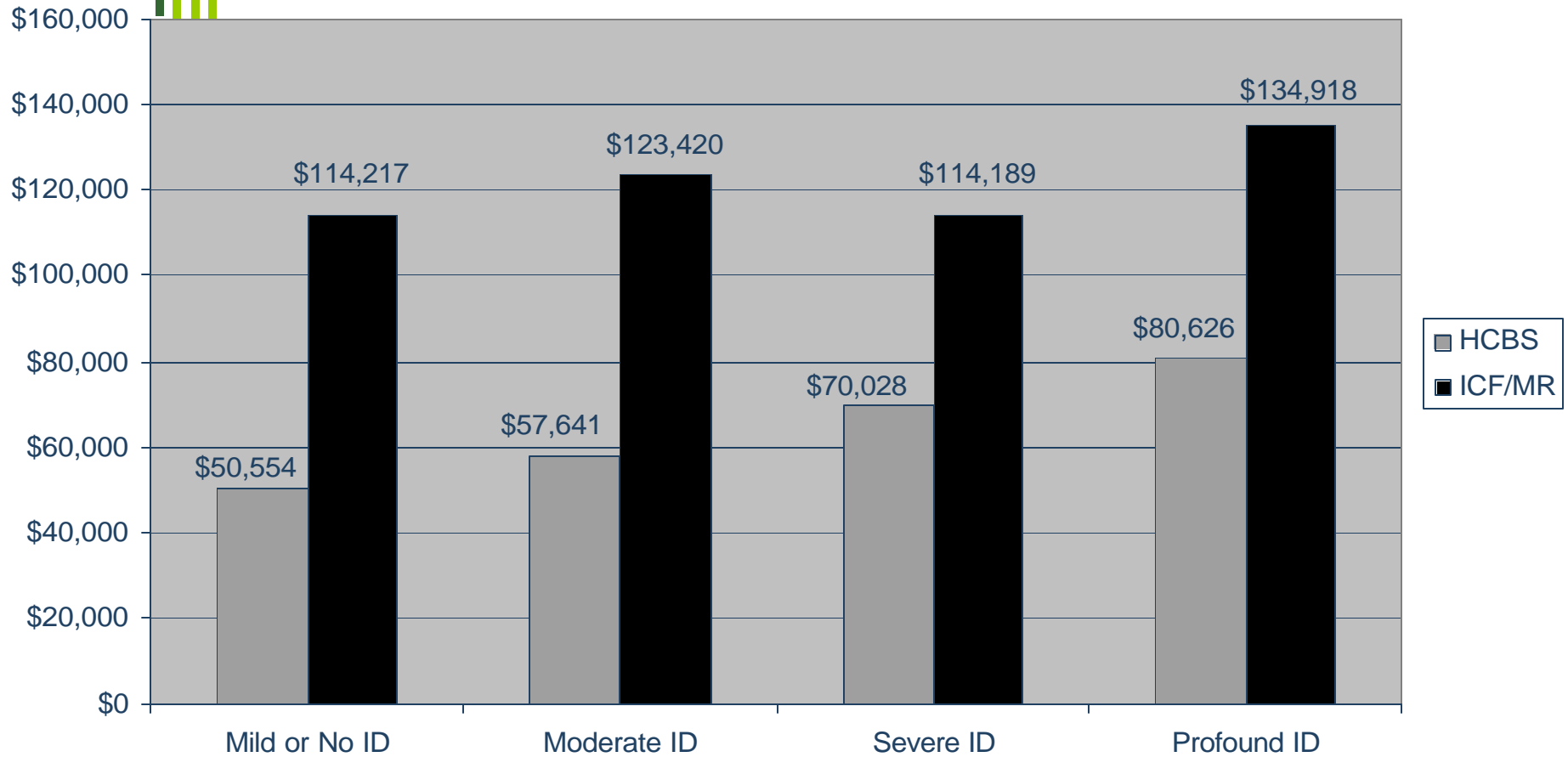


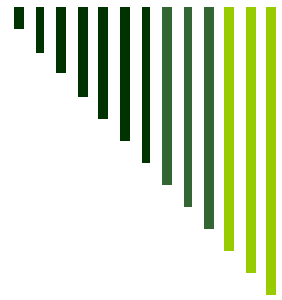
Chart 29. Average Annual Medicaid Expenditures for Adult HCBS and ICF/MR Recipients by Level of ID in Four States





Findings

- Medicaid expenditures higher for ICF/MR recipients even controlling for level of disability
- Most costly setting for HCBS services is in the individuals own home; less costly supports include family care/host homes



Policy Implications

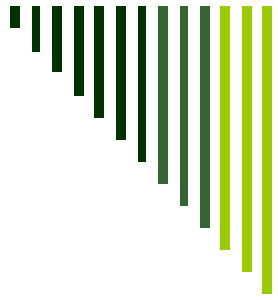
- State systems for people with intellectual and developmental disabilities are already over extended and confront waiting lists. It will be important going forward to allocate resources to those services that support positive outcomes and that provide deliver value for the \$\$ spent.



Summary

- **Need consistent support for HCBS development and CMS initiatives**
 - Self-determination outcomes
 - Expenditures
 - Magnitudes less than overwhelming

- **Much to do in Medicaid LTSS generally and HCBS specifically**
 - Lots of congregate care and facility-based services
 - Choice remains limited for persons with severe disability
 - Routine health and rights standards not always attained



- **Individual characteristics more related to outcomes than service models**
 - **People with more severe disability have less desirable outcomes**
 - **People with dual diagnoses have less desirable outcomes**
 - **The more severe the disability the less influence of service models**



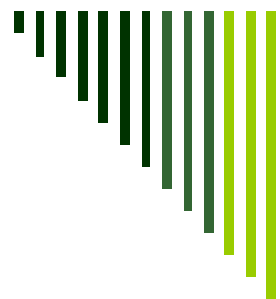
NCI Program as a Vehicle for Research

- **Multi-state sample provided opportunity to examine national goals**
 - **Sample size allowed breakdowns by factors and multivariate analyses**
 - **Choice, independence, inclusion, relationships, productive activity...**
 - **Policy-relevant variables (program size, type, models)**
 - **Individual characteristics for description and controls**
 - **Ability to merge characteristics, outcomes and expenditures**
 - **Flexibility to respond to questions as they arise**



Limitations of the NCI and Multi-State Approach

- Samples of states as “representing” the US
- A few items in the NCI would benefit from more precision
 - Community integration
 - Consumer direction
- Benefits of integrated site- and agency-level independent variables
 - Staffing (e.g., ratios, turnover)
 - Financial (when payment files are not available)



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