

**Medicaid Home and Community-Based
Services for Persons with Intellectual and
Developmental Disabilities:
Background and Findings from Consumer Interviews
and the Medicaid Statistical Information Systems**

Final Report

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This report was authored by K. Charlie Lakin, Robert Doljanac, Soo Yong Byun and Roger Stancliffe of the University of Minnesota and Sarah Taub and Giuseppina Chiri of the Human Services Research Institute.

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EXECUTIVE SUMMARY

This study examined the outcomes of efforts in six selected states to provide Medicaid Home and Community-Based Services (HCBS) and Medicaid Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR) to respond to the needs of and assurances made to people with intellectual and developmental disabilities (ID/DD). It was conducted as part of a larger, comprehensive evaluation of Medicaid Home and Community-Based Services. The purpose of the HCBS evaluation was to study of the impact of Medicaid Home and Community-Based Services programs on quality of life, quality of support, service utilization and cost. The scope of the study included both Medicaid HCBS programs as well as other Medicaid-funded long-term care services. The research focused on Medicaid financing and delivery of services to older and younger people with disabilities in six states, and the Medicaid financing and delivery of services for individuals with intellectual disabilities and developmental disabilities in six other states. The evaluation included individual consumer surveys which were merged with Medicaid MSIS payment file data. The goal of this research is to assist federal and state policy makers in gaining further knowledge about: 1) how Medicaid HCBS program funds are currently used; 2) how programs and policies affect costs, access to needed support and quality of services; and 3) how program design features may be associated with cost-effective use of program options.

This study of the characteristics, service use, experiences, outcomes, satisfactions and expenditures of HCBS and ICF/MR beneficiaries with intellectual and developmental disabilities was based on “consumer interviews” of nearly 3,000 Medicaid HCBS and ICF/MR recipients in Alabama, Kentucky, Indiana, Oklahoma, Massachusetts and Wyoming using the National Core Indicators (NCI) and merged data from sample members’ Medicaid payment files in four of the six states. The study examined the efforts and accomplishments of states in responding to the wide range of needs, desires and expectations of individuals with ID/DD and to the national and state commitments made to them. It further addressed the capacity to do so cost-effectively.

Medicaid funded services for persons with ID/DD have undergone a major shift from larger facilities to supporting people in their family homes, their own homes, and other community residences in the past decade. Medicaid HCBS has been a major contributor to this shift. Since 1992, the number of Medicaid HCBS users with ID/DD has increased by 381,200 people, to 443,608 total recipients in June 2005, while during this same period ICF/MR residents decreased by nearly 45,000 (from 146,300 to 101,800). There has been a corresponding significant growth in HCBS spending (\$1.7 to \$17.2 billion), with much less change in ICF-MR spending (\$8.8 to \$12.1 billion). The findings of this study address the benefits and remaining challenges that accompany these changes.

General Well-Being

Interviews regarding individual well-being and basic health and safety revealed:

- About 89% of HCBS and ICF/MR recipients said they liked where they lived.
 - A somewhat higher proportion of HCBS recipients than ICF/MR recipients (89.3% and 86.0%) reported they liked where they lived.
 - HCBS recipients living with family members were more likely than HCBS and ICF/MR recipients living away from family to report they liked where they lived (95.6% and 87.2%). They were also more likely to report they feel happy, less often afraid at home, less often afraid in the neighborhood and less often lonely.
- 15% of persons living away from family reported that they often or always feel lonely.
- During the year prior to the consumer interviews, the vast majority of HCBS and ICF/MR recipients had physical exams (90.7% and 98.5%), but OB/GYN exams for adult women (70.2% and 87.8%) and dental exams in the previous 6 months (63.9% and 68.8%) were well below recommended standards.
- About 90% of HCBS and ICF/MR recipients report liking their job or other day program in which they participated during the day, and even more (93%) report that most staff supporting them in those activities are nice and polite with higher rating among HCBS recipients (94% and 89%).
- About 7.5% of HCBS and ICF/MR recipients were reported not to have had a routine medical exam in the past year; 35% to have not had a routine dental exam in the past 6 months; about 25% of adult women to have not had an OB/GYN exam in the past year. HCBS recipients were consistently less likely to have routine health and dental exams than were ICF/MR residents.
- More than two-thirds of HCBS and ICF/MR recipients (73% and 70%, respectively) report having friend other than paid staff to talk to and do things with.

Self Determination

Interviews regarding individual choice in daily life and control over or participation in service decisions revealed:

- Almost two-thirds (63.6%) of HCBS and ICF/MR recipients reported they had a role in choosing or changing their direct support staff; ICF/MR residents were more likely to have staff selected exclusively by others than were HCBS recipients (49.0% and 31.5%).
- Only about one-half (51.5%) of HCBS and ICF/MR recipients living away from family reported they chose or participated in the choice of where they lived.

HCBS recipients were more likely to have participated in the choice of their home than ICF/MR recipients (58.1% and 34.1%).

- 62.9% of respondents said they picked staff who help them at home
- 88% of HCBS and ICF/MR recipients chose what to buy with their own spending money either independently or with assistance;
- Nearly one-fifth (19.4%) of HCBS and ICF/MR residents living away from family did not visit any other alternative setting(s) before moving into their present home, with HCBS recipients more likely to have visited other places than ICF/MR residents (84.6% and 68.5%).
- About one-fifth (20.1%) of HCBS and ICF/MR recipients indicated that other people set their daily schedules for going to bed and getting up; control by others of one's daily schedule was much higher in ICFs/MR (44.3%) than for HCBS recipients (12.9%).
- Personal choice in daily life and choice in support-related decisions was considerably higher on average for HCBS than ICF/MR recipients, but after controlling for level of ID, medical support needs, sensory impairments, behavioral and psychiatric conditions choice was more strongly associated with living in a congregate care setting than by whether that congregate care setting was HCBS or ICF/MR funded.

Individual Characteristics

HCBS finances services for people with a full range of disabilities and support needs, but ICF/MR beneficiaries on average on a number of measures exhibited substantially greater levels of impairment than HCBS recipients. Because of the greater total number of HCBS recipients on most of the same measures there were more HCBS than ICF/MR recipients with substantial impairments.

- 14.6% of HCBS recipients were reported to have profound ID as compared with 38.7% of ICF/MR recipients, but of the combined HCBS and ICF/MR samples, 60.2% of the persons with profound ID were HCBS recipients
- 11.3% of HCBS recipients were reported to be non-ambulatory as compared with 20.1% of ICF/MR recipients, but of the combined HCBS and ICF/MR sample 69.5% of persons who were non-ambulatory were HCBS recipients.
- 6.8% of HCBS recipients were reported to require at least weekly care of a nurse and /or physician as compared with 28.1% of ICF/MR residents, but there was no statistical difference in the estimated number of all HCBS and ICF/MR recipients requiring that level of care in HCBS or ICF/MR programs.
- HCBS and ICF/MR recipients were not statistically different in the proportions with visual impairments, cerebral palsy, autism, monthly or more frequent seizures or dual diagnoses of intellectual and psychiatric disabilities, or in the prescription of medication for mood, anxiety or behavior disorders.

Expenditures

- Including Medicaid-financed medical and long-term care supports of sample members in 4 states (Alabama, Kentucky, Oklahoma and Wyoming), HCBS recipients had average annualized expenditures of \$61,770 as compared with \$128,275 for ICF/MR recipients.
- Controlling for level of ID, medical care needs, sensory and physical impairment, behavioral and psychiatric conditions, and type of living arrangement, HCBS vs. ICF/MR participation accounted for only 3.3% of the variance in expenditures.
- Among HCBS recipients average per person expenditures were much more consistently associated with severity of disability than among ICF/MR recipients.
- Adult HCBS recipients individuals living with parents or other family members had average social support and medical expenditures (\$25,072) that were 40.6% of the average expenditure for all HCBS recipients and 19.5% of ICF/MR residents. Persons living in host family or companion arrangements had average social support and medical expenditures (\$44,112) that were 71.4% of the average for all HCBS recipients and 34.4% of the average expenditure for ICF/MR residents.

This study supported the national trend away from institutional (ICF/MR) and to home and community supports (HCBS) for persons with ID/DD by identifying consistent social benefits accruing to individuals and substantial financial benefits accruing to state and federal governments as part of the shift. It should be encouraging that national commitments to community support and inclusion made in ADA, the Olmstead decision, the President's New Freedom Initiative and other legislative sources; the policies promoted by CMS in its Real Choice System Change Grants, Money Follows the Person and other demonstrations; the policy and program directions taken by most states in recent years; and the public interest of cost-effective supports for persons with ID/DD appear to be fully compatible. Continued commitment by CMS to encourage continued HCBS development seems well-founded. The study also demonstrated the value of establishing and maintaining policy-relevant data sets with sufficiently large, representative and multi-state samples to address key topics, such as expenditures, but with the capacity to attend to important demographic and diagnostic subpopulations, service options within larger programs, and other research considerations that may arise. Efforts within CMS to assure ongoing research and evaluation of Medicaid-financed long-term services and supports programs for persons with ID/DD seems essential as total expenditures for the combined the HCBS and ICF/MR programs now exceed \$30 billion dollars per year.

I. INTRODUCTION

Background of Evaluation

This report summarizes outcomes of an evaluation of Medicaid HCBS for persons with intellectual and developmental disabilities (ID/DD) based on a six-state sample of nearly 2,400 HCBS recipients and a comparison sample of about 600 ICF/MR residents. The focus of the study was to examine HCBS as an alternative to ICF/MR in terms of the individuals served, the services provided, the outcomes experienced and the costs incurred. The premise of the evaluation was that Medicaid long-term services and supports for persons with ID/DD should support the attainment of national goals for persons with ID/DD as articulated in major legislation, judicial decisions and executive orders. The study examined individual and program variables associated with various outcomes and expenditures, attempting to balance in the analyses the national promises made to all individuals with ID/DD, but to also control for differences among groups of sample members in examining program-related outcomes.

Policy Background

State and federal policy commitments delineate a clear and unambiguous national agenda for supporting and improving the lives of individuals with intellectual and developmental disabilities (ID/DD) throughout the US. Medicaid services financed by state and federal governments are intended to assure that individuals with ID/DD receive the support and assistance they need in order to live in the most integrated settings appropriate to their needs. The promise of access to and support for integrated community lives and roles for persons with ID/DD is clearly expressed in national legislative, judicial, administrative and other sources that make four basic commitments:

- People with disabilities will live in and participate in their communities;
- People with disabilities will have satisfying lives and valued social roles;
- People with disabilities will have sufficient access to needed support, and control over that support so that the assistance they receive contributes to lifestyles they desire; and
- People will be safe and healthy in the environments in which they live.

These commitments have been articulated in a number of legislative, administrative and judicial statements describing national policy.

Americans with Disabilities Act and Olmstead

In *Olmstead et al. v. L.C. et al.* (527 U.S. 581 [1999]) the U.S. Supreme Court ruled that Title II of the Americans with Disabilities Act (ADA) (42 U.S.C. 12101) required

states to provide the services, programs and activities developed for persons with disabilities in the “most integrated setting appropriate.” In *Olmstead*, the Supreme Court concluded that “unjustified isolation or segregation of qualified individuals with disabilities through institutionalization is a form of disability-based discrimination”.

Presidential Executive Order and the New Freedom Initiative

In June 2001, President Bush signed an Executive Order committing the Executive Branch of the U.S. government to the principal findings of *Olmstead*. The Order stipulated that, “the United States is committed to community-based alternatives for individuals with disabilities and ... seeks to ensure that America’s community-based programs effectively foster independence and participation (Bush, 2001, p.1).”

Developmental Disabilities Assistance and Bill of Rights Act 2000

In the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (PL 106-402; 42 USC 15001), Congress recognized the “national interest” in supporting people to “achieve full integration and inclusion in society...and that “the goals of the Nation properly include the goal of providing individuals with developmental disabilities with the information, skills, opportunities, and support to...live in homes and communities in which such individuals can exercise their full rights and responsibilities as citizens” (Section 101(a)(16)(B)).

The Rehabilitation Act of 1993

Among the Congressional findings of the Rehabilitation Act of 1993 were that disability “in no way diminishes the right of individuals to a) live independently; b) enjoy self-determination; c) make choices; d) contribute to society; e) pursue meaningful careers; and f) enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of American society.” (29 USC 701(a)(2)).

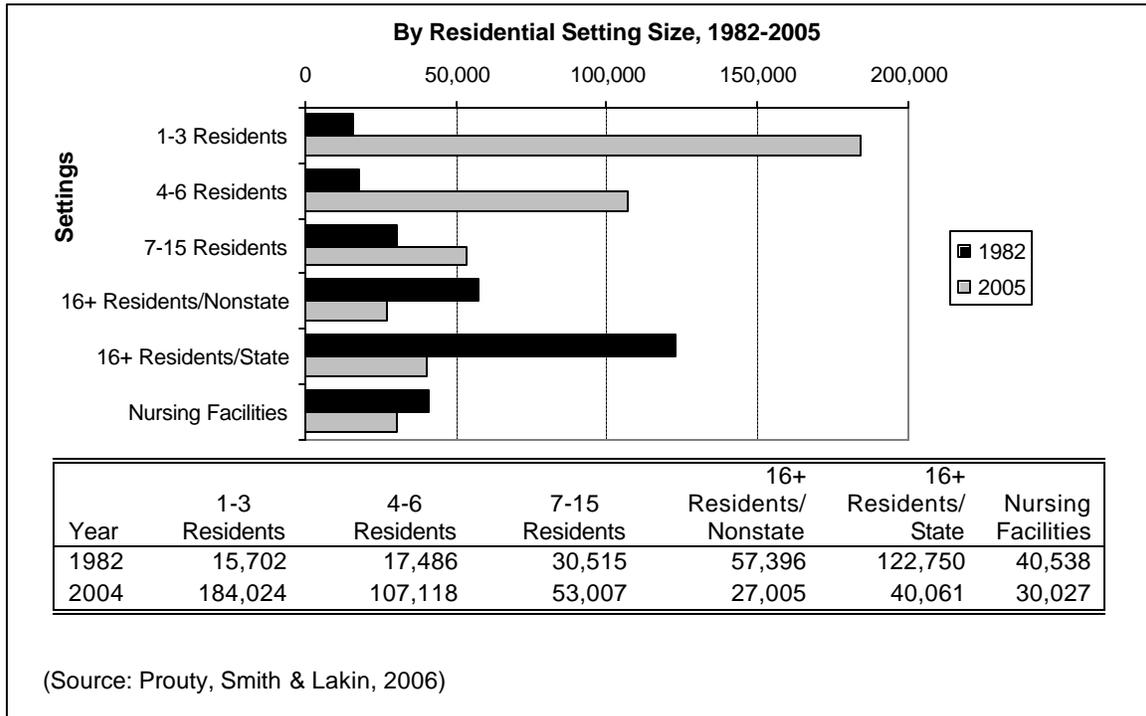
The commitments made in these and other sources of national goals for persons with ID/DD have been evolving, but largely evident for much of the past 2 decades. Their most concrete effects are evident in changing patterns of service and service financing.

Movement From Institutions to Community

Chart 1 shows how substantially the settings of residential and related supports for persons with ID/DD have changed from the fiscal year year (1982) when HCBS-financed supports first became available. Between June 1982 and June 2005, states report that the number of people receiving paid support while living in homes of 3 or fewer persons with ID/DD increased from 15,700 to 184,000; the number in settings with 4 to 6 residents with ID/DD increased from 17,500 to 107,100 persons. In contrast, between 1982 and 2005 persons with ID/DD in public

institutions of 16 or more residents decreased from about 122,750 to 40,050 and persons with ID/DD in private institutions decreased from 57,400 to about 27,000. Persons with ID/DD reported to be residing in nursing facilities are reported to have decreased from an estimated 40,500 to 30,000 (Prouty, Smith & Lakin, 2006).

Chart 1. Changes in Primary Settings of Residential Supports for Persons with ID/DD After the Creation of Medicaid HCBS, June 1982 to June 2005



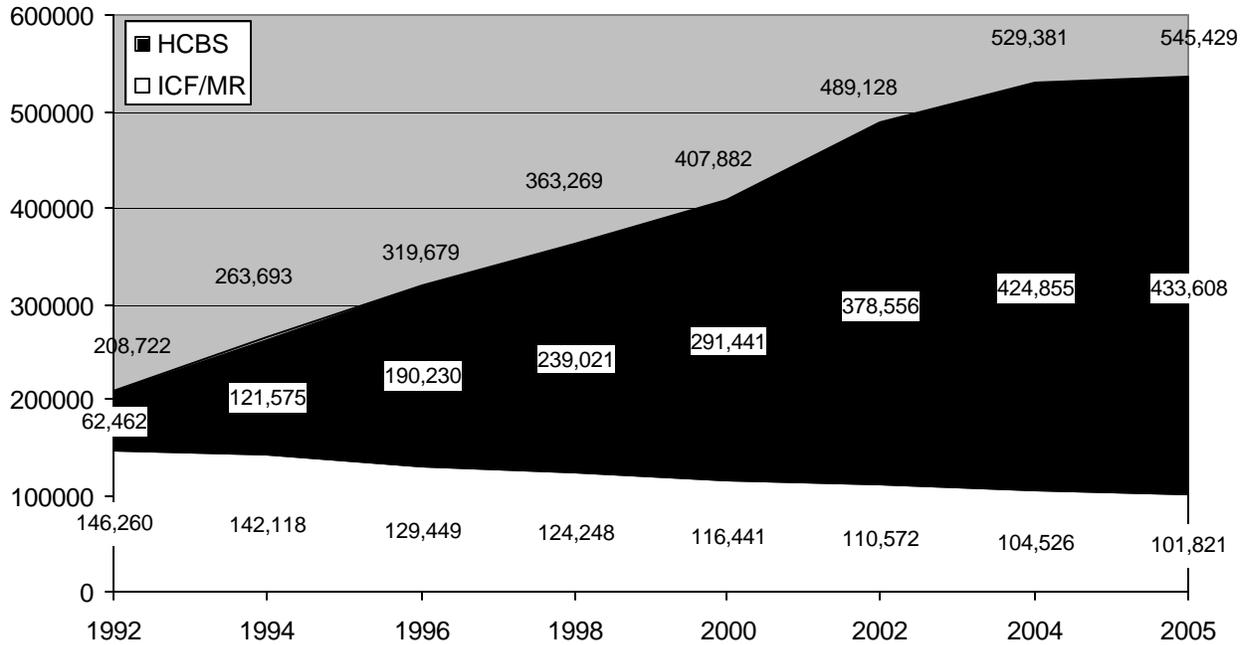
Medicaid HCBS made a major contribution to such shifts, even though these shifts began before 1982 and were supported between 1982 and 1992 primarily by other than Medicaid HCBS financing. The shifts toward small community settings accelerated after 1992 with changes in Medicaid policy that permitted more rapid expansion of Medicaid HCBS-financed services.

Growth and Shifts in HCBS and ICF/MR Recipients

Given its ability to support the kinds of opportunities recognized as important for persons with ID/DD, the HCBS program was recognized from its inception as an important resource for financing alternatives to institutional placements (Greenberg, Schmitz, & Lakin, 1983). Beginning in the early 1990s, requirements that states demonstrate reductions in projected ICF/MR residents and expenditures roughly equal to requested increases in HCBS participants and expenditures were considerably relaxed. They were then completely dropped in the 1994 revisions of the HCBS regulations. As shown in Chart 2 since 1992 there has been rapid growth in the number of Medicaid HCBS recipients in the United States, from about 62,500 in June 1992 to about 443,600 in June 2005. During the same period there has been steady, although much less notable, decrease in the numbers of persons living in ICFs/MR. In June 1992

there were 146,260 ICF/MR residents nationwide; by June 2005 ICF/MR residents had

Chart 2. Changes in Medicaid HCBS and ICF/MR Service Recipients, June 1992-June 2005

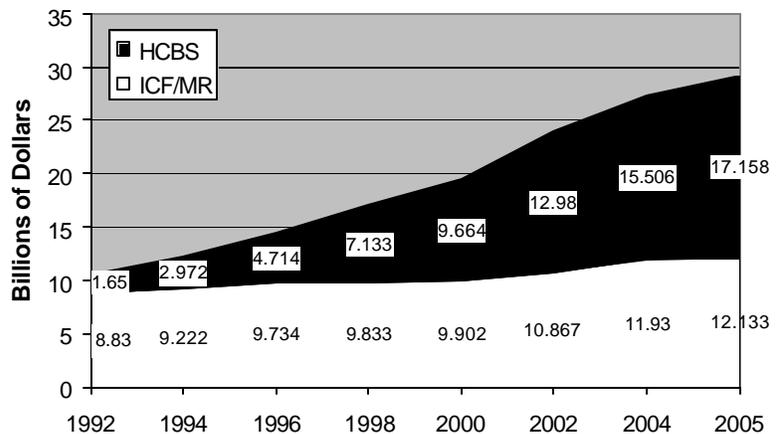


decreased to 101,821. During the 1992-2005 period the combined total of Medicaid HCBS and ICF/MR recipients with ID/DD grew by more than 160%, from 208,700 to 545,400 persons (Prouty, Smith & Lakin, 2006).

Growth and Change in HCBS and ICF/MR Expenditures

Chart 3 shows the changes in annual Medicaid HCBS and ICF/MR expenditures that correspond to the changes in enrollment between Fiscal Year 1992 and Fiscal Year 2005. Between 1992 and 2005 annual federal and state expenditures for Medicaid HCBS and ICF/MR services for people with ID/DD increased from \$10.485 billion to \$29.292 billion. Chart 3 shows how growth in HCBS expenditures made up 82.5% of the growth in combined HCBS and ICF/MR expenditures. It is, however, notable that ICF/MR expenditures increased by

Chart 3. Changes in Medicaid HCBS and ICF/MR Expenditures, FY 1992-FY 2005



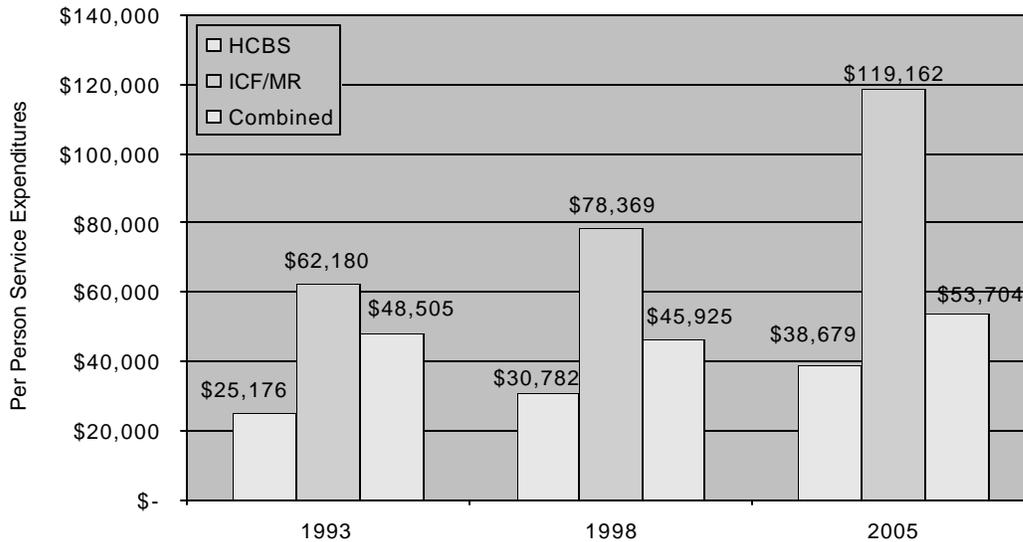
(Source: Prouty, Smith & Lakin, 2006)

37% (\$3.3 billion) over the period, even as total ICF/MR recipients decreased by 30%.

Change in Per Person Expenditures in HCBS to ICF/MR

Chart 4 shows the changes in average per recipient HCBS and ICF/MR expenditures between FY 1993 to FY 2005. The computations are based on fiscal year expenditures divided by the number of June 30 enrollees. Even though during the 1993-2005 period, per person expenditures for both HCBS and ICF/MR increased substantially (by 53.6% and 91.6%, respectively), with the notable shift from ICF/MR to HCBS, the average per recipient expenditure for the combined program increased by only 10.7% in nominal dollars. Controlling for CPI inflation by expressing 1993 expenditures in 2005 dollars, between 1993 and 2005 the combined average per person expenditures for HCBS and ICF/MR actually decreased by 18.1% in real dollars (from \$65,547 to \$53,704). As expenditure breakdowns in this report will suggest, a major factor in this change has been the lower costs of the rapidly increasing number of Medicaid HCBS recipients supported in the homes they share with family members or in host family settings (now an estimated 52% of all HCBS recipients).

Chart 4. Average Annual Expenditures per Medicaid HCBS, ICF/MR and Combined Service Recipients in 1993, 1998 and 2005



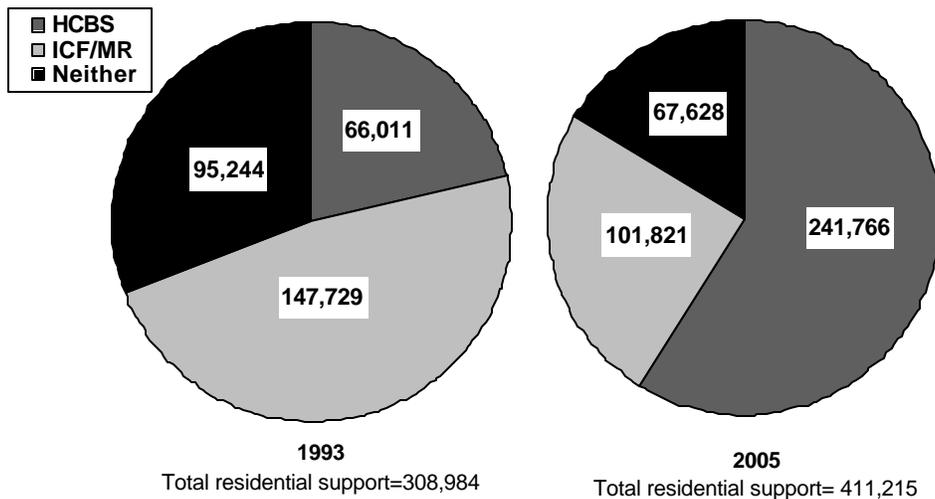
(Source: Prouty, Smith & Lakin, 2006)

Growth in Medicaid Coverage of Services

Chart 5 presents estimates of the extent to which residential supports provided to persons with ID/DD (defined as supports to people not living with parents or other family members) were financed by HCBS and ICF/MR programs. The chart shows both the increasing role of HCBS in financing residential supports for persons with ID/DD (from 21.4% in 1993 to 58.8% in 2005), and the increasing role of Medicaid in general in

financing residential supports for persons with ID/DD (from an estimated 69.2% in 1993 to 83.6% in 2005). During that period the number of persons with residential services not financed by Medicaid HCBS or ICF/MR programs decreased by about 27,600 persons. These reflect opportunities exercised by states to bring services that were previously funded by the states alone under the state-federal cost-sharing provided by Medicaid HCBS. During the 12 year period the total number of persons receiving residential services financed by HCBS and ICF-MR increased by an estimated 129,850 persons.

Chart 5. Numbers and Proportions of Persons with ID/DD Receiving Medicaid-Funded Residential Supports, 1993-2005



(Source: Prouty, Smith & Lakin, 2006)

Changes Within HCBS Program

Clearly there has been a very rapid transformation in relatively few years in Medicaid financing of long-term services and supports for people with ID/DD. The shift from ICF/MR to HCBS recipients has moved with remarkable pace as has the overall expansion of HCBS-financed services. Within the HCBS programs there have been notable changes as well. In June 1992, based on reports of states serving 62.5% of all HCBS recipients, an estimated 21.1% or about 13,200 HCBS recipients nationwide were receiving HCBS while living in a home shared with a parent or other relative (Mangen, Blake, Prouty & Lakin, 1994). By June 2005, based on reports of states serving 76.6% of all HCBS recipients, an estimated 45.5% or about 201,800 HCBS recipients were receiving HCBS while living in a home shared with a parent or other relative (Prouty, Smith & Lakin, 2006). From another perspective from these same reports, in June 1992 including both HCBS and ICF/MR recipients, an estimated 87.5% of Medicaid long-term services and support recipients with ID/DD were living in public or private agency-managed residential facilities; by June 2005, residential facilities residents made up only an estimated 37.6% of combined HCBS and ICF/MR recipients. Numerically in 1992 and 2005 agency-managed residential facility residents were an estimated 182,700 and 204,900 persons, respectively.

It was in the context of rapidly changing HCBS and ICF/MR programs that this study of the characteristics, experiences, and expenditures of HCBS and ICF/MR recipients with ID/DD for this report was conducted. The data collection included a sample of 2,948 HCBS and ICF/MR recipients, 80.2% of whom received HCBS. This is quite similar in proportion to the 80.1% of HCBS recipients among combined HCBS and ICF/MR recipients in 2004 when most of the data collection occurred (Prouty, Smith & Lakin, 2006).

Research Questions

The research questions that guided this study derived both from the outcomes identified in articulated national goals for persons with ID/DD and from the status of HCBS as alternative to ICFs/MR. These questions included:

- What are the demographic, diagnostic, functional, health, behavioral health and sensory characteristics of adult HCBS recipients, and how do these differ from the characteristics of ICF/MR residents?
- To what extent do HCBS recipients experience choice and control in the decisions of their everyday lives (“personal choice”) and about their services and service providers (“support-related choice”); how do these differ according to individual characteristics and circumstances; and how do they compare with ICF/MR residents?
- To what extent do HCBS recipients find satisfaction in their supports, experience a sense of well-being and receive the related social and health supports that protect their well-being; how do these differ according to individual characteristics and circumstances; and how do they compare with ICF/MR residents?
- To what extent do HCBS recipients experience social and family relationships, community inclusion and integrated employment; how do these differ according to individual characteristics and circumstances; and how do they compare with ICF/MR residents?
- To what extent do individuals with dual diagnoses of intellectual and psychiatric disability, autism and other conditions experience service access, and service and lifestyle outcomes that are different than persons without such conditions; and how are these different for individuals receiving HCBS and ICF/MR services?
- What are the costs of Medicaid long-term services and “other Medicaid” services for HCBS and ICF/MR recipients of different characteristics and living arrangements; what individual and service factors are most predictive of expenditures; and how do HCBS and ICF/MR expenditures compare when such differences are controlled?

II. METHODS

General Approach

This report summarizes data on the efforts and accomplishments of six states in using the Medicaid options for persons with ID/DD, especially HCBS, to realize the national expectations of inclusion, participation, contribution, exercise of rights and self-determination. This evaluation is based primarily on data gathered with a “consumer interview” protocol used with 2,948 randomly selected individuals in 6 purposely chosen states. The data were accessed through an ongoing program known as the National Core Indicators (NCI). The purposely selected states included 6 states with an ongoing evaluation programs using the common data elements and methodologies of the National Core Indicators Consumer Survey protocol. The selected states were chosen for regional variation and relative range of HCBS development, i.e., extent to which HCBS-financed services are the predominant approach to service development. The six selected states were Alabama, Indiana, Kentucky, Massachusetts, Oklahoma and Wyoming. The dates of the consumer interviews conducted in these states varied with all occurring between October 2003 and November 2005. The data collection period in each state of one to three months.

The merging of NCI Consumer Surveys from these 6 states provided an opportunity to examine service and support outcomes (inclusion, community participation, life satisfaction, productivity, self-determination, health and safety, etc.) as they relate to state, Medicaid option (HCBS, ICF/MR), individual characteristics (functional, behavioral, health, demographic and diagnostic descriptors) and service-related variables (types of living arrangement, day activity). In addition to the individual interviews, payments for Medicaid services were merged with NCI records of all sample members in 4 of the 6 states (Alabama, Kentucky, Oklahoma, Wyoming). Payment records were for the year preceding the consumer interviews.

State Sample

Selection of states for inclusion in the consumer interview study was based on the following criteria: a) they were among the 17 states in which NCI surveys were at the time being conducted on a random sample drawn from a population that included all institution and community service recipients in the state; b) they provided regional variation; c) they represented relatively urban and relatively rural states; d) they represented states with variations in ethnicity; and e) they represented variability in the relative mix of institutional and community services. States selected (and the reasons for their selection) are introduced below.

Massachusetts. Massachusetts has made major commitments to community living for persons with ID/DD. Between 1993 and 2003 it reduced populations of person living in ID/DD institutions of 16 or more residents from 8,200 to 1,200. In 2004,

the state conducted 766 Consumer Surveys across the entire service population.

Kentucky. Kentucky was relatively late in major community service development in the past decades, but it has demonstrated in recent years notable acceleration. This shift in policy and program development has been funded primarily by the Medicaid HCBS program with a doubling of HCBS recipients between June 1999 and June 2003. In 2004, 507 Consumer Surveys were conducted across the entire service population.

Indiana. Indiana provides for an relatively large proportion of community service recipients in group homes, of 7 or more residents. It was relatively late in taking advantage of the Medicaid HCBS option, but has had a 4-fold growth in HCBS in just the past few years. In 2004, the state conducted 815 Consumer Surveys.

Alabama. Alabama has made steady progress in deinstitutionalization, institutional closures, community service development and use of HCBS funding. Between 1994 and 2004 it reduced its state institution population from about 1,150 to 200 and its ICF/MR recipients from 1,150 to 225. Nearly half of its HCBS recipients live with family members. In 2004, the state completed 401 Consumer Surveys.

Oklahoma. Oklahoma has been affected by significant requirements of federal courts on its service system. Although these requirements have led to major reductions in state institution populations, Oklahoma has large numbers of service recipients living in private institutions. In 2004, a total of 401 Consumer Surveys were completed.

Wyoming. Wyoming has undergone enormous change since 1990. Initially propelled by a court case, Wyoming has in the past 15 years begun from scratch to develop a highly regarded community, service system. It has one of the nation's highest per capita rates of access to services and few persons waiting for service. In 2004, a total of 401 Consumer Surveys were administered.

Medicaid program change in the six state sample. The rates of change in HCBS and ICF/MR programs among the 6 sampled states and the USA as a whole between 1996 and 2004 are summarized in Table 1. It shows how both the USA and the sample states experienced very rapid growth in HCBS programs between 1996 and 2004 and substantial decreases in ICF/MR service recipients. As a group sample states added 55.5% of their total 2004 HCBS recipients after FY 1996. In the USA as a whole, HCBS recipients grew by 43.7% after 1996. ICF/MR residents in the 6 sample states decreased by 31.1% between 1996 and 2004 as compared with 23.8% in the entire USA.

Table 1. Comparison of HCBS and ICF/MR Program Size in 2004 and Change Since 1996 Among Sampled States and the USA

HCBS Recipients				ICF/MR Recipients			
States		USA		Six States		USA	
2004	(%Change)	2004	(%Change)	2004	(%Change)	2004	(%Change)
35,451	(+55.5%)	424,855	(+43.7%)	8,391	(-31.1%)	104,526	(-23.8%)

Individual Sample Members

In four states (Alabama, Kentucky, Oklahoma, Wyoming) Medicaid payment files were used to identify individuals in the NCI data sets who were either HCBS or ICF/MR participants at the time of their NCI interview. In Massachusetts and Indiana, service setting level staff identified individuals as HCBS, ICF/MR or “other” program participants. These designations were confirmed based on information provided by states on the sizes, and housing types and sponsoring organizations that could be assumed to be (or assumed not to be) either HCBS or ICF/MR financed. In some instances, indications of “Don’t Know” or missing data on HCBS, ICF/MR or “other” findings could not be supplied from state level program descriptions. Without individual identifiers these individuals were dropped from the sample. There were 40 such individuals.

The final 6 state sample of services and support recipients who completed NCI interviews included 3,291 individuals. Of these 2,948 (89.6%) were HCBS or ICF/MR recipients. These final sample members included 343 from Alabama, 811 from Indiana, 298 from Kentucky, 712 from Massachusetts, 390 from Oklahoma and 390 from Wyoming. Sample members included 2,365 HCBS recipients and 583 ICF/MR recipients.

The mid-point of the NCI consumer surveys used in this study was late 2003-early 2004. In June 2004 nationwide, states reported 424,855 HCBS recipients and 104,526 ICF-MR recipients (80.2% HCBS). In the 6 sampled states in June 2004, there were reported to be 33,875 HCBS recipients and 8,391 ICF/MR recipients (80.1% HCBS). Within the 6-state sample of HCBS and ICF/MR recipients, the 2,365 HCBS recipients comprised 80.2% of the sample. In general, then, the distribution of HCBS and ICF/MR recipients among the sample members from the 6 states was nearly identical to the distribution of the HCBS and ICF/MR populations in those 6 states, and to the national population.

Individual Outcomes Assessment

National Core Indicators (NCI)

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 are gathered with a common instrumentation package has been shown to meet accepted standards as being both valid and reliable. The instrumentation is accompanied by a standard training program for interviewers, including training manuals, presentation slides, training video, scripts for scheduling interviews, lists of frequently asked questions, picture response formats, and additional resource materials on interviewing persons with disabilities. A sampling manual is also provided to state teams as part of the training program.

Summary of data elements. NCI **Descriptive data elements** include demographic variables (age, ethnicity, gender, etc.), functioning (mobility, vision, hearing, etc.), diagnostic (level of intellectual disability, cerebral palsy, autism, etc.), behavioral (mental health/psychiatric diagnosis, medications for behavior problems, frequency of disruptive, self-injurious behavior, etc.). **Service use variables** include the types of services/service sites used and needed, frequency of health and dental services, attitudes about and satisfaction with services and service providers, involvement and satisfaction with case managers, choice of services, service sites and service providers, use of consumer direct options and HCBS or ICF/MR financing of services. **Service and lifestyle outcome variables** include measures of friendships, community participation, family involvement, participation in a self-advocacy choice in home, jobs, schedule of activities, and use of funds measures of respect, employment earnings and so forth. **Satisfaction variables** include individual reports of satisfaction/liking of home, job and support providers, feelings of safety at home and in the community, sense of loneliness, getting help when needed, opportunities to do new things and so forth.

Individual respondents. Capturing and describing individual outcomes and satisfaction is the core purpose of NCI. Many of the core indicators are measured by items that obtain information directly from individuals receiving services. The consumer interview consistently yields high response rates, individuals with ID/DD can respond to the questions in the protocol. Average percentage of individuals who are able to respond to Section I of the survey (which only allows responses from individuals receiving services) falls between 65-70%. For the 30-35% that are not able to respond on their own, Section II may be answered by someone who knows the individual well on his or her behalf. The questions in Section I focus on the individual's subjective perceptions about services and lifestyle, while the Section II items are more factual.

Variations in item response on qualitative/subjective items. Reporting on subjective aspects of service quality and lifestyle satisfaction is a significant challenge for many individuals with intellectual disability. The nature of ID makes certain questions about abstract concepts such as "satisfaction with services" difficult to understand and respond to. There are documented tendencies toward certain response patterns (e.g., repeating back the last alternative posed and trying to provide an interviewer the answer "desired"). These tendencies have been well-documented for more than 25 years (e.g., Sigelman, et al., 1981), but understanding them does resolve them. At the same time, it is increasingly recognized that the best designed efforts possible must be made to gather as much information as individuals can provide about their own "consumer experience." The NCI protocol attempts to define "satisfaction" with various aspects of service and lifestyle with concepts and words that are most readily recognized by respondents (e.g., "Are staff nice to you?"). Efforts have been made to minimize the demands of understanding and responding to questions. The response types are mixed so that fixed response patterns are not facilitated. Consistency checks with recurring items are built into the survey. Despite these efforts to maximize the number of individuals who can reliably and validly respond to the items posed, it is recognized that about 30% to 35% of state samples will not be able to respond depending on the item. Interviewer impressions and the internal consistency checks are used by interviewers to determine whether an item should be asked or whether responses obtained should be treated as valid. The result of these challenges and efforts made to

assure that meaningful responses are obtained, is that on items related to service and lifestyle satisfaction response rates are substantially lower for certain groups (e.g., people with severe and profound ID) and such limitations are passed through to affect other groupings (e.g., there is a higher percentage of persons with severe and profound ID in ICF/MR settings than among HCBS recipients). This means that a smaller percentage of ICF/MR sample have responded to qualitative questions about service and lifestyle quality than of the HCBS sample, although both groups of respondents share the characteristic of responding reliably according to the consistency check items and being judged by the interviewer to understand the questions posed.

Reliability and Validity of the Consumer Interview

Basic reviews and psychometric testing has been conducted on the NCI to establish its reliability and validity. The NCI Consumer Survey was developed with extensive involvement of a Program Advisory Committee (PAC) and other advisors to assure that the outcomes that were the foundation of the NCI instrument validly represented the established goals for contemporary services. The individual data elements were developed with ongoing review to assure that the items asked of individuals validly represent the outcomes desired and that the responses obtained provided usable and useful information about such outcomes.

Reliability. NCI survey underwent a series of reliability tests: in October 1997, a pilot test was conducted with thirty individuals in Connecticut. A sample of 30 individuals was selected to include 15 consumers who were expected to be able to respond and 15 consumers who were not expected to be able to respond to the questions. Inter-rater reliability resulted in 93% agreement between the two raters. In November 1998, inter-rater and test-retest reliability data was collected in Nebraska. This inter-rater reliability test (of 25 interviewees) resulted in 93% agreement between the raters, and an average kappa score of 0.794. Test-retest reliability (N=27) resulted in 80% agreement between the two administration times, and an average kappa score of 0.502. In April 1999, an inter-rater reliability test was conducted with 27 individuals in Minnesota. An analysis of inter-rater reliability found 92% agreement between raters.

Validity of interviews. The project uses a number of strategies to monitor that the data collected are valid. First, NCI project staff conduct a “train the trainer” sessions and provide a set of training materials to all states so that all interviewers receive consistent training. The training includes instruction on basic skills for interviewing persons with developmental disabilities and question-by-question review of the survey tool. Second, interviewers are asked to give formal input on every interview conducted. At the end of Section I, there are two questions that ask the interviewer to make a judgment about the individual’s comprehension of the questions and consistency of responses. In addition, interviewers complete a Feedback Sheet at the end of every interview. This information helps project staff improve the survey questions and instructions each year. In order to reduce coding errors all states are supplied with standard data entry materials, including codebooks that outline the required variable formats and response codes and Microsoft Access databases with controlled data entry

forms. The NCI program in its years of development and implementation has been tested and refined in more than 30,000 assessments of individual outcomes.

Medicaid Expenditure Data

The addition to demographic, diagnostic, functional, health, behavioral, service use, lifestyle and satisfaction data from the NCI, Medicaid expenditure data were linked to each sample member's record in 4 of the six states. (In 2 states consent for the NCI interview did not to include an agreement for such data use.) The expenditure analyses in this report are based on a sample of 1,421 HCBS and ICF/MR service recipients in Alabama, Kentucky, Wyoming and Oklahoma. By agreement prior to implementing the study, specific identification of these states is not included in the analyses. The entire state samples in these states included 1,710 individuals, of whom 83.0% were recipients of HCBS or of ICF/MR financed services. The National Core Indicator (NCI) and the Medicaid Payment File data sets were merged based on Social Security numbers to create a data set that included comprehensive information on the characteristics, service use, financing and expenditures for individuals with ID/DD in the selected states. Once merged the Social Security members and state identifiers were stripped from both data sets. Although a total of 1,421 sample members were identified as either HCBS or ICF/MR recipients, because of missing variables some analyses included fewer sample members.

Within each of the four states Medicaid payments were extracted for each individual sample member on whom there was a NCI interview and who was participating in either the Medicaid HCBS or ICF/MR program in the month of the NCI interview. Once state payment data were submitted by the states to the Centers for Medicare and Medicaid Services (CMS) and passed through the CMS VALIDS process for basic editing and consistency checks, they were posted for project access. The actual months in the individuals' payment record created for each sample member included the HCBS and ICF/MR payments and the Medicaid state plan services made on behalf of that individual in the 12 months prior to the mid-point of the NCI interviews conducted in that individual's state.

Categorizing Expenditures

With assistance from officials in each of the four participating states, procedure codes for each service in state's current HCBS program were assigned to one of 12 service categories. These categories included 1) residential services, 2) personal assistance, 3) respite care, 4) employment and day services, 5) nursing services, 6) therapy services, 7) environmental modifications, 8) supplies and equipment, 9) transportation, 10) training, 11) case management, and 12) other. The assignment of the various state services into a common set of categories permitted comparisons across states and aggregation of expenditures of similar types of service. Payment files were also used to obtain Medicaid ICF/MR and "other Medicaid" expenditures for sample members. "Other Medicaid" expenditures were Medicaid expenditures for individuals that were not included in HCBS or ICF/MR payments. They included expenditures in 6 categories: a) prescription medications, b) medical expenses, c) social services, d)

personal care, e) home health care, and f) therapies.

Annualized Payment Variable

Within the 4 states, there were 36 sample members who spent part of the year in an ICF/MR and part of the year receiving HCBS services. In all of these instances the individual began the year receiving ICF/MR services (i.e., having ICF/MR payments at the beginning of the year) and ended the year receiving HCBS-financed services. As noted the NCI interviews took place at the end of the year for which payments were recorded. Therefore, for these 36 sample members the NCI data gathered reflected their service characteristics and experiences with their HCBS financed services, but their HCBS payment files reflected less than a year of HCBS expenditures. In 90 other instances, people entered the HCBS and ICF/MR program during the year in which payments were being aggregated so that they had fewer than 12 full months of payments. To be able to generate consistent descriptions of expenditures and to make comparisons across programs, a common expenditure variable was created.

Because considerable variation was noted among individual service recipients in the amount of their monthly claims, it was assumed that annual expenditures would provide the most valid and stable measure of an individual's expenditures. An annual expenditure variable was created by summing all monthly expenditures in the year prior to the NCI data collection to yield the annual expenditures of all sample members. It was further necessary to "annualize" expenditures for persons receiving Medicaid HCBS and ICF/MR for less than a full year. This involved computing the average monthly expenditure for the actual months of services received by recipients with less than a full year of HCBS or ICF/MR payments and then multiplying the average monthly payments by 12 months. For the purposes of these analyses the "annualized payment" variable used for each sample number reflects the annualized cost of services for that individual in the program (HCBS or ICF/MR) in which the person was participating at the time of the NCI data collection.

III. FINDINGS

Demographic and Diagnostic Characteristics

Table 2 presents comparisons of HCBS and ICF/MR sample members on a number of demographic and disability related descriptors. These descriptors include: age, gender, level of intellectual disability, psychiatric diagnosis, autism, cerebral palsy and seizure or other neurological disorders.

Table 2. Selected Characteristics of Adults (18 and Older) with ID/DD Receiving Medicaid HCBS and ICF/MR Services in Six States

Characteristics	HCBS		ICF/MR		Total		Sig.
	N	%	N	%	N	%	
Age							
Average Age	42.25		45.38		43.77		t=-5.227***
18 to 54	1,947	83.4	445	77.5	2,392	82.3	?2=10.961**
55 and older	387	16.6	129	22.5	516	17.7	
Total	2,334	80.3	574	22.6	2,908	100.0	
Gender							
%Male	1,340	56.9	334	57.3	1,674	57.0	?2=.033
%Female	1,016	43.1	249	42.7	1,265	43.0	
% of Total	2,356	80.2	583	19.8	2,939	100.0	
Level of ID							
Mild	955	40.6	149	25.6	1,104	37.7	?2=199.916***
Moderate	603	25.7	87	14.9	690	23.5	
Severe	352	15.0	110	18.9	462	15.8	
Profound	334	14.2	221	38.0	555	18.9	
None	48	2.0	4	0.7	52	1.8	
(Not Reported)	(58	2.5)	(11	1.9)	(69	2.4)	
Reported Total	2,350	80.2	582	19.8	2,932	100.0	
Psychiatric Diagnosis							
No	1,576	69.4	387	66.7	1,963	68.9	?2=1.539
Yes	695	30.6	193	33.3	888	31.1	
% of Total	2,271	79.7	580	20.3	2,851	100.0	
Autism							
No	2,107	93.8	514	93.8	2,648	93.8	?2=.000
Yes	140	6.2	36	6.2	176	6.2	
% of Total	2,247	79.3	577	20.4	2,824	100.0	
Cerebral palsy							
No	1,939	86.0	472	81.9	2,411	85.2	?2=6.056*
Yes	315	14.0	104	18.1	419	14.8	
% of Total	2,254	79.6	576	20.4	2,830	100.0	
Seizure or Neurological Disorder							
Disorder Reported	735	33.0	240	41.9	975	34.8	?2=15.78***
1 or more seizures/month	228	10.0	50	9.0	278	9.8	

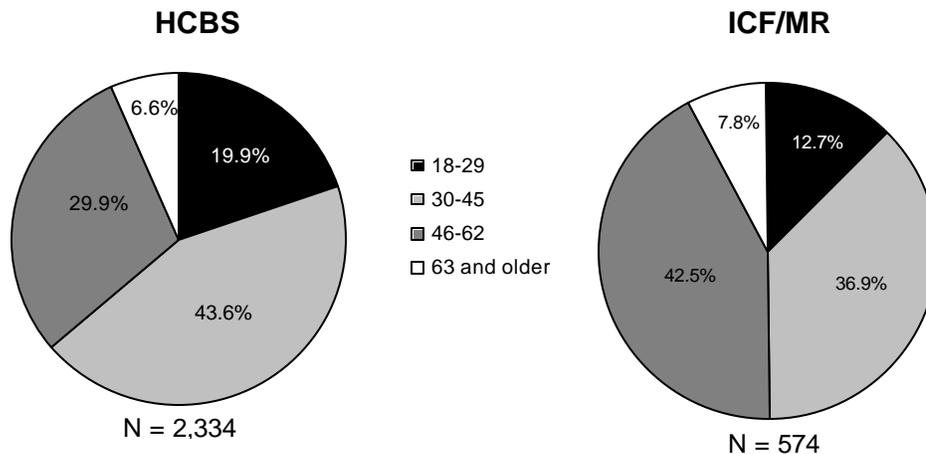
*p<.05; **p<.01; ***p<.001

Age Distribution

Table 2 and Chart 6 show the age distribution of ICF/MR and HCBS recipients in the sample. Adult ICF/MR recipients were older than HCBS recipients with an average age of 45.4 years as compared with 42.2 years. While 63.5% of the HCBS sample fell in the 18-45 year age group only 49.6% of ICF/MR residents did. In contrast, 42.5% of ICF/MR sample fell between 46 and 62 years as compared with 29.9% of HCBS recipients. An estimated 50.3% of ICF/MR residents were 46 or older as compared to 36.5% of HCBS recipients. An estimated 7.8% of ICF/MR residents were 63 years or older as compared with 6.6% of HCBS recipients. It should be noted that had all ages of HCBS and ICF/MR recipients (rather than just adults) had been included in the sample,

the average age of HCBS recipients would have been decidedly younger given the frequent use of HCBS by states to finance home-based supports for children with ID/DD and the decreasing use of ICF/MR placements for children and youth in favor of settings that provide more culturally typical developmental experiences.

Chart 6. Age Distributions of Adult HCBS and ICF/MR Recipients in Six States



Gender

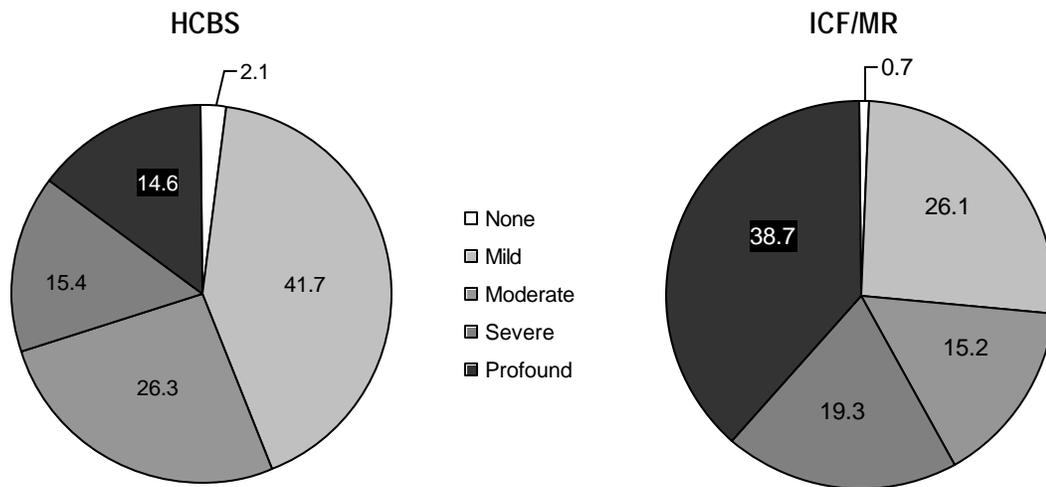
As expected, the majority (57.0%) of the ICF/MR and HCBS service recipients were males. There were no statistically significant differences in the gender distributions of HCBS and ICF/MR.

Presence and Level of Intellectual Disability

Relatively few of either the HCBS or ICF/MR recipients were reported to have developmental disabilities but not intellectual disabilities (1.8%). There were major differences in the distributions by level of ID of HCBS and ICF/MR recipients. These are shown in Chart 7 with persons with unreported ID (2.4%) excluded. An estimated 41.7% of adult HCBS recipients had mild intellectual disability (ID), generally defined by an IQ range of about 54 to 70, or no intellectual disability, as compared with 26.1% of ICF/MR residents. An estimated 26.3% of HCBS recipients had moderate ID, generally defined by an IQ in the range of about 37-53, as compared with an estimated 15.2% of the ICF/MR residents. In contrast about 30.0% of HCBS recipients were indicated to have severe or profound ID, that is, IQ's below 36, as compared with an estimated 58.0% of ICF/MR recipients. There was a much higher proportion of persons with profound ID in the ICF/MR sample (38.7%) than among adults receiving HCBS (14.6%), but, because of the greater number of persons served by HCBS, the number of persons in the sample (and in the estimated population) with profound ID was greater in HCBS than in ICF/MR programs (about 60.2% and 39.8%, respectively). Still, the markedly different distribution of HCBS and ICF/MR recipients based on level of ID, and as will be noted

the substantial differences in service outcomes for individuals with different levels of ID irrespective of HCBS or ICF/MR program participation, require that such differences be accounted for in comparisons of HCBS and ICF/MR service outcomes.

Chart 7. Distribution of Adult HCBS and ICF/MR Recipients by Level of Intellectual Disability



Other Conditions

Psychiatric diagnoses. An estimated 31.1% of HCBS and ICF/MR recipients in the 6 states had reported psychiatric diagnoses reported in their treatment records in addition to ID/DD.. The reported differences in “dual diagnoses” between HCBS and ICF/MR recipients (30.6% and 33.3%, respectively) were not statistically significant.

Autism. An estimated 6.2% of HCBS and ICF/MR recipients in the 6 states were indicated in their treatment records to have autism. There were no reported differences between HCBS and ICF/MR recipients (6.2% of both).

Cerebral Palsy. An estimated 14.8% of HCBS and ICF/MR recipients in the 6 states had cerebral palsy. Cerebral palsy was somewhat more prevalent ($p < .05$) among ICF/MR residents than HCBS recipients (18.1% and 14.0%, respectively).

Seizures or neurological disorders. As estimated 34.8% of HCBS and ICF/MR recipients in the 6 states were reported to have seizure or neurological disorders. Such disorders were more prevalent ($p < .001$) among ICF/MR residents than HCBS recipients (41.9% and 33.0%, respectively). However, an estimated 9.8% of HCBS and ICF/MR recipients were reported to actually experience one of more seizures per month. In this the differences between the HCBS and ICF/MR samples were not statistically significant.

Vision, Mobility and Medical Needs

Table 3 presents comparisons of HCBS and ICF/MR sample members on visual, mobility and medical descriptors.

Table 3. Visual, Mobility and Medicaid Needs of Adults (18 and Older) with ID/DD Receiving HCBS and ICF/MR Services in Six States

Characteristics	HCBS		ICF/MR		Total		Sig.
	N	%	N	%	N	%	
Vision Level							
Sees Well with or without Lenses	2,097	89.1	494	84.9	2,591	88.5	$\chi^2=9.378^{**}$
Vision Problems Limit Some Activities	138	5.9	53	9.1	191	6.5	
Very Limited/Legally Blind	118	5.0	35	6.0	153	5.2	
% of Total	2,353	80.2	582	19.8	2,935	100.0	
Mobility							
Ambulatory	2,095	88.7	465	79.9	2,560	87.0	$\chi^2=31.875^{***}$
Non-ambulatory	267	11.3	117	20.1	384	13.0	
% of Total	2,362	80.2	582	19.8	2,944	100.0	
Requires Care of Nurse or Physician							
Less than Once/month	1,824	78.6	319	55.3	2,143	74.0	$\chi^2=312.056^{***}$
At least Once/month	338	14.6	96	16.6	434	15.0	
At least Once/week	97	4.2	33	5.7	130	4.5	
At least Once/day	31	1.3	63	10.9	94	3.2	
24-Hour Immediate Access	30	1.3	66	11.4	96	3.3	
% of Total	2,320	80.1	577	19.9	2,897	100.0	

p<.01; *p<.001

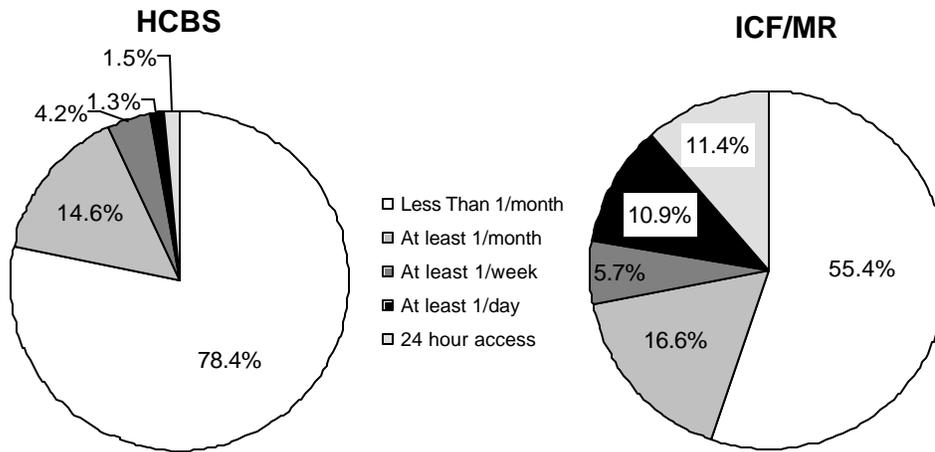
Vision. HCBS and ICF/MR recipients were similar in their rated levels of functional vision. A total of 88.5% of HCBS and ICF/MR recipients were reported to see well with or without corrective lenses. About 5.2% were reported to be blind, legally blind or to have very limited vision, and 6.5% to have vision problems that limited some activities. Small differences were noted between HCBS and ICF/MR recipients with ICF/MR recipients having more vision problems that limited activities (10.9% and 15.1%, respectively; p<.001).

Mobility. The vast majority (87.0%) of HCBS and ICF/MR recipients were reported to be ambulatory (able to walk with or without assistance or aids). HCBS recipients were more likely (p<.001) to be ambulatory than were ICF/MR recipients: 88.7% of the HCBS recipients were able to walk independently with or without aid as compared with 79.9% of ICF/MR recipients.

Frequency of medical care. Table 3 and Chart 8 show the reported frequency with which HCBS and ICF/MR recipients in the sample required the medical care of nurses or physicians. Notable differences were reported. The 78.6% of adult HCBS recipients reported to need the medical care of a nurse or physician less than once a month, was substantially (p<.001) greater than the 55.3% reported for ICF/MR residents. In contrast, 28.1% of ICF/MR recipients were reported to require at least weekly care of

a nurse or physician as compared with 6.8% of HCBS recipients. Very large differences were reported in those needing at least daily care (22.3% of ICF/MR residents and 2.6%

Chart 8. Frequency of Required Medical Care from Nurses and/or Physicians of HCBS and ICF/MR Recipients



of HCBS recipients), and in those needing 24-hour intermediate access to care (11.4% and 1.3%). It cannot be determined, of course, whether regulatory requirements and the presence of on-site nursing staff within larger ICFs/MR contributed to the differences in reported need.

Cerebral Palsy, Down Syndrome and Non-Verbal Communication

Table 4 presents the estimated number of and proportion of adult HCBS and ICF/MR recipients with cerebral palsy, Down syndrome and non-verbal communication. About 14.8% HCBS and ICF/MR recipients had cerebral palsy with no significant differences among HCBS and ICF/MR recipients. Adult HCBS recipients were more likely ($p < .001$) than ICF/MR residents to have Down syndrome (10.3% and 5.1%). ICF/MR recipients were more likely than HCBS recipients ($p < .001$) to communicate non-verbally (23.3% and 19.0%, respectively). As in many such comparisons, however, the substantial majority of non-verbal communicators in the sample were HCBS recipients (69.8%).

Table 4. Cerebral Palsy, Down Syndrome and Non-Verbal Communicators Among Adults Receiving HCBS and ICF/MR Services in Six States

Condition	HCBS		ICF/MR		Total		Sig.
	N	%	N	%	N	%	
Cerebral Palsy							
No	1,939	86.0	472	81.9	2,411	85.2	? $\chi^2=6.06^{***}$
Yes	315	14.0	104	18.1	419	14.8	
Total	2,254	100.0	576	100.0	2,830	100.0	
Down Syndrome							
No	1,842	89.7	483	94.9	2,325	90.7	? $\chi^2=13.16^{***}$
Yes	212	10.0	26	5.1	238	9.3	
Total	2,054	100.0	509	100.0	2,563	100.0	
Non-Verbal							

No	447	19.0	193	33.3	640	21.8	?2=55.53***
Yes	1,905	81.0	387	66.7	2,292	78.2	
Total	2,352	100.0	580	100.0	2,932	100.0	

*** p<.001

Racial/Ethnic Characteristics

Table 5 presents racial and ethnic distributions of HCBS and ICF/MR sample members. Racial categories included are White, Native American, Asian/Pacific Islander, African American and Other or Two Races Listed. An ethnic breakdown is also presented for Hispanics/Non-Hispanics. The 89.6% of sample members who were indicated to be white was considerably greater than the 84.2% of the total population of the 6 states that was white. One factor in the difference between representation of whites among the sample of service recipients and in the general population was probably that an adult population of an average of 44 years was studied. There is generally a higher proportion of adults among white population as contrasted with the minority groups shown in Table 5. But differences in access may also exist. There were no statistically significant differences by race or by Hispanic ethnicity in the likelihood of being an HCBS and ICF/MR recipient.

Table 5. Reported Race/Ethnicity of Adults (18 and Older) with ID/DD Receiving Medicaid HCBS and ICF/MR Services in Six States

Characteristics	HCBS		ICF/MR		Total		Sig.
	N	%	N	%	N	%	
Race							
Native American	44	2.1	9	1.7	53	2.0	?2=5.372
Asian/Pacific Islander	15	0.7	1	0.2	16	0.6	
Black/African American	126	6.1	44	8.2	170	6.5	
White	1,850	89.8	476	88.6	2,326	89.6	
Other or Two or Listed Races	25	1.2	7	1.3	32	1.2	
% of Total	2,060	79.3	537	20.7	2,597	100.0	
Ethnic Group							
Non-Hispanic	2,270	97.3	574	98.6	2,844	97.6	?2=3.446
Hispanic	63	2.7	8	1.4	71	2.4	
% of Total	2,333	80.0	582	20.0	2,915	100.0	

Behavioral Characteristics and Challenges

Table 6 presents a summary of behavioral characteristics of HCBS and ICF/MR sample members in three areas: 1) self-injury, 2) disruptive behavior, and 3) uncooperative behavior.

Table 6. Behavioral Characteristics of Adults with ID/DD Receiving Medicaid HCBS and ICF/MR Services in Six States

Characteristics	HCBS		ICF/MR		Total		Sig.
	N	%	N	%	N	%	
Self-Injury							
No	1,868	82.1	461	69.2	2,329	79.2	?2=52.286***
Yes	406	17.9	205	30.8	611	20.8	
At least monthly	241	61.6	111	55.0	352	59.4	?2=3.167
At least weekly	98	25.1	64	31.7	162	27.3	
At least daily	45	11.5	23	11.4	68	11.5	
At least hourly	7	1.8	4	2.0	11	1.9	
% of Total	391	65.9	202	34.1	593	100.0	
Disruptive Behavior							
No	1,488	65.6	361	54.2	1,849	62.9	?2=28.432***
Yes	782	34.4	305	45.8	1,087	37.0	
At least monthly	438	56.6	150	49.3	588	54.5	?2=11.912**
At least weekly	223	28.8	119	39.1	342	31.7	
At least daily	101	13.0	29	9.5	130	12.1	
At least hourly	12	1.6	6	2.0	18	1.7	
% of Total	774	71.8	304	28.2	1,078	100.0	
Uncooperative behavior							
No	1,477	65.2	401	60.2	1,878	64.1	?2=5.588*
Yes	788	34.8	265	39.8	1,053	35.9	
At least monthly	402	51.3	135	51.1	537	51.3	?2=1.235
At least weekly	260	33.2	86	32.6	346	33.0	
At least daily	113	14.4	38	14.4	151	14.4	
At least hourly	8	1.0	5	1.9	13	1.2	
% of Total	783	74.8	264	25.2	1,047	100.0	

*p<.05, **p<.01; ***p<.001

Note: The total number of those who are reported to have specific behavioral characteristics is slightly less than the totals of reported frequency due to missing data.

Self Injury

Self-injurious behavior includes biting or scratching oneself, head banging, puncturing ones own skin or other actions of purposeful injury to oneself. About one-fifth (20.8%) of HCBS and ICF/MR recipients are reported to engage in self-injury. The 30.8% of ICF/MR recipients who were reported to engage in self injury was considerably (p<.001) greater than the 17.9% of HCBS recipients, but among ICF/MR and HCBS recipients who engaged in self-injurious behavior the reported frequencies were not statistically different. While residents in ICFs/MR had a higher probability of engaging in self-injury at least daily (4.1% of ICF/MR recipients and 2.3% of HCBS recipients), because HCBS recipients are so much more numerous, 65.8% of the persons in the total sample who were reported to injure themselves at least daily were supported

by HCBS.

Disruptive Behavior

Disruptive behavior was defined as behavior that interferes with the activities of others, including starting fights, yelling and screaming, disturbing things that others are working on and so forth. Higher rates of disruptive behavior were reported for adults in ICFs/MR than among HCBS recipients ($p < .001$). Specifically, 45.8% of ICF/MR residents were reported to engage in disruptive behavior as compared with 34.4% of HCBS recipients. Of persons reported to exhibit disruptive, ICF/MR recipients were also more likely to engage in disruptive behavior weekly or more often than HCBS recipients (50.7% and 43.4%, respectively). Again, however numerically more individuals reported to have high frequency disruptive behavior were supported by HCBS than ICF/MR (e.g., 76.4% of those reported to be disruptive to others on at least a daily basis were HCBS recipients).

Uncooperative Behavior

Uncooperative behavior refers to behavior involving rule breaking, cheating, defiance, stealing. There were small differences ($p < .05$) between HCBS and ICF/MR recipients in the reported tendency to engage in uncooperative behavior (34.8% and 39.8%, respectively), but no significant differences in reported frequencies.

Psychiatric Diagnoses and Behavioral Medications

Table 7 summarizes the numbers and proportions of HCBS and ICF/MR samples whose treatment records indicated a “dual diagnosis.” Dual diagnosis refers to people who have formal diagnoses of a mental health/psychiatric disability and an intellectual disability. People with other multiple diagnoses (e.g., cerebral palsy and intellectual disability) are not included in this category. The reported differences in dual diagnosis among HCBS recipients (30.8%) and ICF/MR residents (33.6%) were not statistically significant.

Table 7. Dual Psychiatric and Intellectual Disability Diagnoses Among Adults Receiving Medicaid HCBS and ICF/MR Services in Six States

Diagnoses	HCBS		ICF/MR		Total		Sig.
	N	%	N	%	N	%	
Dual Diagnosis	663	30.8	190	33.6	853	31.4	
ID Only	1,492	69.2	375	66.4	1,867	68.6	?2=1.17
% of Total	2,155	100.0	565	100.0	2,720	100.0	

* $p < .05$

Dual Diagnosis and Level of ID

Table 8 summarizes the distributions of HCBS and ICF/MR recipients with and without dual diagnoses by level of intellectual disability. It shows that dual diagnoses were relatively more prevalent among individuals with mild ID and among residents of ICF/MR. Dual diagnoses were reported for 37.4% of HCBS recipients with mild or no ID and for 49.0% of ICF/MR recipients. An estimated 32.1% of sample members with moderate ID had a dual diagnosis including 46.5% of ICF/MR residents and 29.9% of HCBS recipients. Dual diagnoses were less common among individuals with severe and profound ID (29.2% and 16.6%, respectively). Although prevalences of dual diagnosis were substantially higher for ICF/MR residents of all levels of ID, except severe, the overall reported prevalence of dual diagnoses among HCBS and ICF/MR residents was quite similar (30.8% and 33.6%, respectively). This relates to the much higher percentage of HCBS recipients with mild ID in which the prevalence of reported dual diagnosis is considerably higher (39.0% for sample members with mild ID and 26.3% for all others).

Table 8. Proportion of HCBS and ICF/MR Recipients with Dual Diagnoses by Level of Intellectual Disability in Six States

Level of ID and Dual Diagnosis Status	HCBS		ICF/MR		Total		Stat. Sig.
	N	%	N	%	N	%	
Mild ID							
Dual diagnosis	350	37.4	73	49.0	423	39.0	?2=7.271 **
ID only	586	62.6	76	51.0	662	61.0	
Total and % of all	936	86.3	149	13.7	1085		
Moderate ID							
Dual diagnosis	172	29.9	40	46.5	212	32.1	?2=9.461 **
ID only	403	70.1	46	53.5	449	67.9	
Total and % of all	575	87.0	86	13.0	661		
Severe ID							
Dual diagnosis	98	29.2	32	29.4	130	29.2	?2=.001
ID only	238	70.8	77	70.6	315	70.8	
Total and % of all	336	75.5	109	24.5	445		
Profound ID							
Dual diagnosis	43	14.0	45	20.4	88	16.6	?2=3.802 *
ID only	265	86.0	176	79.6	441	83.4	
Total and % of all	308	58.2	221	41.8	529		
Total							
Dual Diagnosis	663	30.8	190	33.6	853	31.4	?2=3.802 *
ID Only	1,492	69.2	375	66.4	1,867	68.6	
Total and % of all	2,155	79.2	565	20.8	2,720	100.0	

*p<.05; **p<.01

Challenging Behaviors Among Persons With and Without Dual Diagnosis

Table 9 shows frequencies of reported challenging behavior among HCBS and ICF/MR recipients with and without dual diagnosis. The challenging behaviors shown (self-injury, disruptive behavior and uncooperative behavior) are ones of particular significance to the level of staff attention provided to individuals receiving long-term services and supports. Persons with a psychiatric diagnosis in their records consistently were reported to have higher levels of challenging behavior ($p < .001$). These differences were consistently evident across all three behavioral categories and in both HCBS and ICF/MR programs. Only 28.1% of persons with dual diagnosis in the combined HCBS and ICF/MR were reported to exhibit none of the 3 categories of challenging behavior monthly or more often as compared with 55.5% of individuals without a mental health/psychiatric diagnosis.

Table 9. Frequency of Challenging Behavior Among HCBS and ICF/MR Recipients With and Without Dual Diagnosis

Characteristics	HCBS			ICF/MR			Total		
	Dual (N=650)	ID Only (N=1460)	Total (N=2,100)	Dual (N=186)	ID Only (N=372)	Total (N=558)	Dual (N=836)	ID Only (N=1832)	Total (N=2658)
Self-Injurious Behavior¹									
None/Less Than Monthly	75.1%	83.5%	80.9%	59.1%	76.6%	70.8%	71.5%	82.1%	79.1%
Monthly/Less Than Weekly	17.4%	9.2%	11.8%	22.0%	12.9%	15.9%	18.4%	9.9%	12.7%
At Least Weekly	7.5%	7.3%	7.3%	8.6%	3.0%	4.8%	3.5%	2.7%	2.9%
Disruptive Behavior²									
None/Less Than Monthly	49.1%	74.1%	64.7%	34.5%	66.8%	55.9%	45.8%	70.4%	62.9%
Monthly/Less Than Weekly	30.4%	15.5%	20.2%	33.8%	15.8%	21.8%	31.2%	15.6%	20.6%
At Least Weekly	20.5%	11.4%	15.1%	31.7%	17.4%	22.2%	23.0%	14.0%	16.5%
Uncooperative Behavior³									
None/Less Than Monthly	49.4%	70.9%	64.4%	45.5%	72.0%	63.5%	49.2%	71.1%	62.2%
Monthly/Less Than Weekly	26.0%	14.2%	17.9%	29.7%	13.7%	19.1%	26.8%	14.1%	18.1%
At Least Weekly	24.6%	14.9%	17.8%	24. %	14.2%	17.4%	24.0%	14.8%	17.7%
No Challenging Behaviors*⁴	30.2%	55.7%	47.8%	20.9%	54.8%	43.5%	28.1%	55.5%	46.9%

¹ $\chi^2(2)=30.67, p < .001$; ² $\chi^2(2)=100.81, p < .001$; ³ $\chi^2(2)=89.17, p < .001$; ⁴ $\chi^2(2)=118.16, p < .001$

*None reported monthly or more often

Medications for Mood, Anxiety and Behavior

Table 10 summarizes the proportions of HCBS and ICF/MR sample members taking medications because of disorders of mood, anxiety or behavior.

Medications for mood and anxiety disorders. About 35% of both HCBS and ICF/MR recipients were reported to receive medications for mood disorders; about 25% for anxiety. The differences between HCBS and ICF/MR recipients were not statistically significant.

Medication for problem behaviors. Medications to respond to problem behavior were reported to be prescribed to about 30% of all HCBS and ICF/MR recipients. Medications were more commonly ($p < .001$) prescribed to ICF/MR residents than to HCBS recipients (34.9% and 28.6%, respectively). However, as noted in Table 6 the frequency of self-injury and self disruptive behavior was also reported to be higher among ICF/MR residents, and at ratios similar to the differences in ratios of medications administered for problem behavior.

Table 10. Prescribed Medications for Mood, Anxiety, or Behavior of HCBS and ICF/MR Recipients in Six States

Medications for:	HCBS		ICF / MR		Total		Sig.
	N	%	N	%	N	%	
Mood Disorders							
No	1482	65.2%	369	64.7%	1851	65.1%	$X^2 = .038$
Yes	792	34.8%	201	35.3%	993	34.9%	
% of Total	2274	80.0%	570	20.0%	2844	100.0%	
Anxiety							
No	1,668	73.9%	446	78.5%	2,114	74.9%	$X^2 = 5.068^{**}$
Yes	588	26.1%	122	21.5%	710	25.1%	
% of Total	2256	79.90%	568	20.1%	2,824	100.0%	
Behavior Problems							
No	1,607	71.0%	376	66.3%	1,983	70.1%	$X^2 = 4.772^{**}$
Yes	656	29.0%	191	33.7%	847	29.9%	
% of Total	2,263	80.0%	567	20.0%	2,830	100.0%	

** $p < .01$

Dual diagnosis and medications. Table 11 summarizes the percentages of HCBS and ICF/MR recipients with and without dual diagnoses using prescribed medications for three types of disorders (mood, anxiety and behavioral). It also summarizes the proportions of recipients with medications for any one of these disorders. As expected there was a much higher percentage of prescribed medications for persons with dual diagnoses in all three categories. About 69.0% of persons with dual diagnoses took medications for mood disorders as compared with 20.0% of persons with no mental illness diagnosis. About 49.3% of persons with dual diagnosis were prescribed medications for anxiety as compared to 14.6% of those with no mental health diagnosis.

About 55.0% of persons with dual diagnosis were prescribed medications for behavioral disorders as compared with 19.4% of persons with no mental health diagnosis. Altogether 86.7% of individuals with dual diagnosis were prescribed medication for either mood, anxiety or behavior as compared with 31.7% of all other HCBS and ICF/MR recipients. A slight majority (50.8%) of all HCBS and ICF/MR recipients took no prescribed medications for mood, anxiety or behavior. Differences between HCBS and ICF/MR program participants in the uses of medications for mood, anxiety and behavior within dual diagnosis/no dual diagnoses groups were small with the exception of higher rates of prescriptions for anxiety reported for HCBS recipients with dual diagnosis (53.0% as compared with 37% among ICF/MR recipients). Overall use of medication among HCBS and ICF/MR recipients with and without dual diagnosis for any of the 3 conditions was remarkably similar.

Table 11. Percentage of HCBS and ICF/MR Recipients With and Without Dual Diagnoses Taking Prescribed Medication for Mood, Anxiety and/or Behavior Disorders in Six States

Characteristics	HCBS			ICF/MR			Total		
	Dual	ID Only	Total	Dual	ID Only	Total	Dual	ID Only	Total
Mood Disorder¹	(N=664)	(N=1430)	(N=2074)	(N=186)	(N=369)	(N=555)	(N=830)	(N=1799)	(N=2629)
No Medications Takes	30.1%	79.8%	64.4%	33.9%	81.0%	65.2%	31.0%	80.0%	64.4%
Medications	69.9%	20.2%	35.6%	66.1%	19.0%	34.8%	69.0%	20.0%	35.6%
Anxiety Disorder²	(N=627)	(N=1431)	(N=2056)	(N=184)	(N=369)	(N=552)	(N=811)	(N=1799)	(N=2610)
No Medications Takes	47.0%	84.9%	73.4%	63.0%	87.2%	79.2%	50.7%	85.4%	74.6%
Medications	53.0%	15.1%	26.6%	37.0%	12.8%	20.8%	49.3%	14.6%	25.4%
Behavioral Disorder³	(N=627)	(N=1439)	(N=2066)	(N=184)	(N=367)	(N=551)	(N=811)	(N=1806)	(N=2617)
No Medications Takes	46.1%	81.0%	70.4%	41.3%	79.0%	66.4%	45.0%	80.6%	69.5%
Medications	53.9%	19.0%	29.6%	58.7%	21.0%	33.6%	55.0%	19.4%	30.5%
Medication for Any Above⁴	(N=656)	(N=1454)	(N=2110)	(N=189)	(N=370)	(N=559)	(N=845)	(N=1824)	(N=2669)
No Medications Takes	13.1%	67.9%	50.9%	13.2%	69.7%	50.6%	13.1%	68.3%	50.8%
Medications	86.9%	32.1%	49.1%	86.8%	30.3%	49.4%	86.9%	31.7%	49.2%

¹ $\chi^2(1)=477.56, p<.001$; ² $\chi^2(1)=319.79, p<.001$; ³ $\chi^2(1)=254.66, p<.001$; ⁴ $\chi^2(2)=542.61, p<.001$

Lifestyle and Service-Related Satisfaction and Quality

This section summarizes the responses of individual HCBS and ICF/MR recipients to questions related to their perceptions of services and lifestyle and to other service quality-related questions. The reports are limited to individuals who were determined to be able to reliably respond to the questions posed. Response rates for the items varied from 61.7% to 76.2% depending on the nature and complexity of the specific questions. Responses to individual questions were highly related to level of intellectual disability. As an example on the item asking about whether people liked their current home, valid responses ranged from 97.3% of sample numbers with mild ID, 88.5% of sample members with moderate ID, 58.9% of sample members with severe ID

and 20.3% of persons with profound ID. Relatedly, response rates varied from 80.9% of HCBS recipients to 60.0% of ICF/MR recipients. Obviously such differences were statistically significant ($\chi^2(3) = 117.2, p < .001$ and $\chi^2(1) = 117.2, p < .001$, respectively).

Categories in Residential Life and Resident Characteristics

In this study the places of residential living for HCBS and ICF/MR recipients were categorized into 4 basic types. These were: 1) congregate/agency operated housing, 2) host family (also referred to foster care, shared living or companion living), 3) own home (the individual's residence is owned or rented by the individual, and 4) family home (the individual lives with parents or other relatives).

Type of Housing and Level of ID. Table 12 presents a breakdown of these types of residence for HCBS and ICF/MR recipients by level of ID. (ICF/MR residents were all in facilities classified as congregate or agency operated housing.) As shown in Table 12, 56.1% of combined HCBS and ICF/MR recipients lived in settings classified as congregate/agency housing. This included 45.1% of HCBS recipients. As noted before had the sample included individuals younger than 18 years the percentage of persons living in the family home would have been substantially higher. It is notable that individuals in congregate care, both HCBS and ICF/MR tend to have greater degrees of intellectual impairment. However, host family residents were nearly one-third persons with severe or profound ID. Persons in their own homes tended to have the least severe intellectual impairment, but more than one-fifth was indicated to have severe or profound ID. Adult HCBS recipients living with family members also tended to have less severe ID. There was considerably more similarity among HCBS and ICF/MR recipients in congregate care than among HCBS recipients in other types of housing and ICF/MR residents.

Table 12. Distribution of HCBS and ICF/MR Recipients by Home Type and Level of Intellectual Disability in Six States

Home Type	HCBS		ICF/MR		Total	
	N	%	N	%	N	%
Congregate/Agency						
Mild+	378	36.8	153	26.8	531	33.3
Moderate	266	25.9	87	15.3	353	22.1
Severe	189	18.4	110	19.3	299	18.7
Profound	193	18.8	220	38.6	413	25.9
Total	1026	100.0%	570	100.0%	1596	100.0%
Host Family						
Mild+	63	34.8	-	-	63	34.8
Moderate	59	32.6	-	-	59	32.6
Severe	33	18.2	-	-	33	18.2
Profound	26	14.4	-	-	26	14.4
Total	181	100.0%	-	-	181	100.0%
Own Home						
Mild+	337	61.1	-	-	337	61.1
Moderate	95	17.2	-	-	95	17.2

Severe	52	9.4	-	-	52	9.4
Profound	68	12.3	-	-	68	12.3
Total	552	100.0%	-	-	552	100.0%
Family Home						
Mild+	215	41.7	-	-	215	41.7
Moderate	179	34.8	-	-	179	34.8
Severe	75	14.6	-	-	75	14.6
Profound	46	8.9	-	-	46	8.9
Total	515	100.0%	-	-	515	100.0%
Total						
Mild+	993	43.7	153	26.8	1146	40.3
Moderate	599	26.3	87	15.3	686	24.1
Severe	349	15.3	110	19.3	459	16.1
Profound	333	14.6	220	38.6	553	19.4
Total	2274	100.0%	570	100.0%	2844	100.0%

Note: "Mild+" refers to persons with mild or no intellectual disability

Type of residential life and ages of recipients. Table 13 presents a breakdown of HCBS and ICF/MR recipients by age and type of residential setting. It shows a very similar age pattern between residents HCBS and ICF/MR funded congregate/agency housing, with half of congregate care residents (50.4%) between the ages of 31 and 49 years, and an estimated 34.7% 50 years and older. HCBS recipients living with family members tended to be the youngest group with about 90% being 49 years or younger and nearly one-third (32.3%) being 30 years and younger. Host families were supporting the largest proportion of HCBS recipients 50 years and older (35.2%). Congregate/agency homes were the most commonly used residential setting for all age groups, with the exception of 18-30 year olds who had a statistically equal probability (36.5%) of living in their family home.

Table 13. Distribution of HCBS and ICF/MR Recipients by Age and Home Type in Six States

Home Type/Age	HCBS		ICF/MR		Total	
	N	%	N	%	N	%
Congregate/Agency						
18-30 years	168	16.2	73	12.7	241	14.9
31-49 years	517	49.7	296	51.7	813	50.4
50+ years	355	34.1	204	35.6	559	34.7
Host Family						
18-30 years	42	23.1	-	-	42	23.1
31-49 years	76	41.8	-	-	76	41.8
50+ years	64	35.2	-	-	64	35.2
Own Home						
18-30 years	83	14.7	-	-	83	14.7
31-49 years	335	59.5	-	-	335	59.5
50+ years	145	25.8	-	-	145	25.8
Family Home						

18-30 years	171	32.3	-	-	171	32.3
31-49 years	305	57.5	-	-	305	57.5
50+ years	54	10.2	-	-	54	10.2
Total						
18-30 years	464	20.0	73	12.7	537	18.6
31-49 years	1233	53.3	296	51.7	1529	52.9
50+ years	618	26.7	204	35.6	822	28.5

Satisfaction and Choice in Residential Life

Table 14 presents differences in responses of HCBS and ICF/MR recipients to questions about their homes.

Likes home. As shown high percentages of both HCBS and ICF/MR recipients reported that they liked living where they currently live (89.4% and 85.2%, respectively); only small minorities reported not liking where they live (5.0% and 9.5%, respectively). The differences between HCBS and ICF/MR recipients in satisfaction with their homes were quite small but statistically significant. These responses are also summarized in Chart 9.

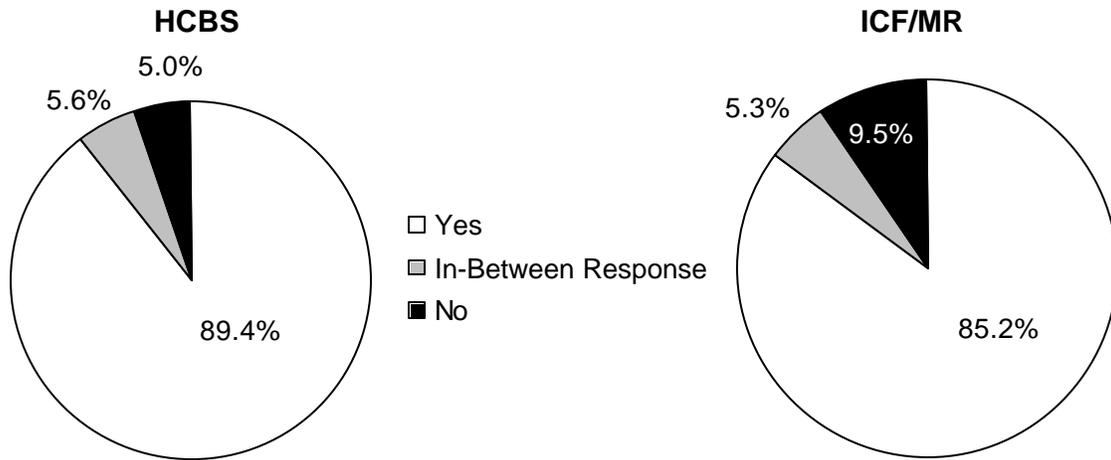
Table 14. Satisfaction, Choice, and Independence in HCBS and ICF/MR Recipients in Residential Life in Six States

Question & Response	HCBS		ICF/MR		Total		Sig.
	N	%	N	%	N	%	
Do you like your home or where you live							
Yes	1,513	89.4%	304	85.2%	1,817	88.6%	X ² =10.934 **
In -between	95	5.6%	19	5.3%	114	5.6%	
No	85	5.0%	34	9.5%	119	5.8%	
% of Total	1,693	82.6%	357	17.4%	2,050	100.0%	
Who chose the place where you live							
Person chose without help	273	15.6%	51	9.2%	324	14.1%	X ² =67.914 ***
Person had some input	723	41.4%	154	27.8%	877	38.1%	
Someone else chose	751	43.0%	349	63.0%	1,100	47.8%	
% of Total	1,747	75.9%	554	24.1%	2,301	100.0%	
How many places did you visit before moving here							
Looked at more than one	516	34.6%	113	29.7%	629	33.6%	X ² =23.946 ***
Visited only one other place	727	48.8%	162	42.6%	889	47.5%	
No, did not visit other places	248	16.6%	105	27.6%	353	18.9%	
% of Total	1,491	79.7%	380	20.3%	1,871	100.0%	
Do you choose who helps you at home							
Yes, person chooses staff	339	19.3%	36	6.5%	375	16.2%	X ² =53.803

Staff assigned but can be changed	832	47.3%	285	51.2%	1,117	48.3%	***
No, someone else chooses	587	33.4%	236	42.4%	823	35.6%	
% of Total	1,758	75.9%	557	24.1%	2,315	100.0%	

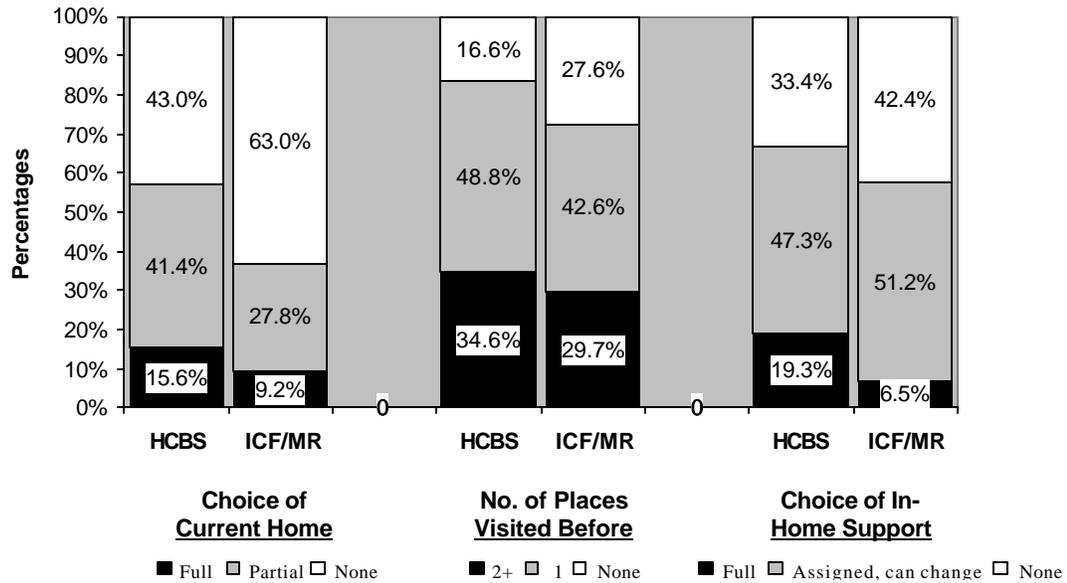
p<.01; *p<.001

Chart 9. Expressed Satisfaction of HCBS and ICF/MR Recipients with the Place they are Living in Six States (excludes people living with relatives)



Choice of home. As shown in both Table 14 and Chart 10, by contemporary standards and assurances of choice, many HCBS and ICF/MR recipients have less choice than might be expected. Although HCBS recipients were considerably more likely than ICF/MR residents to have participated in choosing their homes, only about 57% of HCBS recipients were reported to have chosen their home on their own or to have participated in the decision. This was still considerably more than in the 37.0% of ICF/MR residents. These differences were also reflected in responses to questions about the number of places sample members had visited before moving into their current home. Excluding HCBS recipients living with family members, 16.6% of HCBS recipients were reported not to have visited any other place before moving into their current home as compared with 27.6% of ICF/MR residents.

Chart 10. Reported Opportunities for Choice in Housing Among HCBS and ICF/MR Recipients in Six States



Choice of staff. HCBS recipients were also considerably more likely than ICF/MR residents to have chosen their support staff: 19.3% of HCBS recipients were reported to have been engaged in choosing their staff as compared with 6.5% of ICF/MR recipients. Nearly half of the sample members were reported to have staff assigned by an agency, but to be able to change staff members if not satisfied with those who were assigned (47.3% of HCBS and 51.2% of ICF/MR sample members, respectively). About one-third (33.4%) of HCBS recipients and 42.4% of ICF/MR recipients were reported to have no choice in their direct support staff members.

A Note on Choice and Independence

In this study a number of comparisons of choice and independence are made between HCBS and ICF/MR programs and among different types of settings without controlling for factors shown in the same study to be associated with choice and independence. In other analyses such controls are provided through breakdowns by level of intellectual disability and through multiple regression analyses in which individual characteristics associated with selected outcomes are entered in blocks before program variables such as ICF/MR or residential setting. Both approaches are used because both seem warranted. When assurances of choice and independence are made to people they are not made conditional on achieving a certain intellectual level and much has been written and demonstrated about how with skilled support, all people can be viewed as making or participating in the choices in their lives. In that sense choice is not conditional on any degree of cognitive development. At the same time in this sample (and in other research), the reality is that, individual characteristics (especially level of ID) are powerful predictors of certain outcomes. In this study both perspectives are viewed as important to describing the findings for certain considerations and both are included here.

Sense of Well-being and Security

General sense of well-being and security. Table 15 presents responses of HCBS and ICF/MR recipients to questions reflecting their basic sense of security and well-being. These questions were asked only of individual service recipients who were able to respond on their own behalf. Those responding to items in Table 15 made up only 62.4% to 65.8% of the total sample depending on the specific item. Overall HCBS and ICF/MR respondents reported high levels of well-being on the questions posed, with little difference between HCBS and ICF/MR respondents.

Table 15. Reported Perceptions of Security and Well-Being of HCBS and ICF/MR Recipients in Six States

Question & Response	HCBS		ICF/MR		Total		Sig.
	N	%	N	%	N	%	
Are you feeling happy or sad today							
I feel happy	1,224	82.1%	275	78.8%	1,499	81.5%	X ² =2.394
In-between	186	12.5%	54	15.5%	240	13.1%	
I feel sad	80	5.4%	20	5.7%	100	5.4%	
% of Total	1,490	81.0%	349	19.0%	1,839	100.0%	
Do you ever feel lonely							
No, not often	853	55.1%	157	47.9%	1,010	53.8%	X ² =7.681 *
Sometimes	484	31.3%	128	39.0%	612	32.6%	
Yes, often	211	13.6%	43	13.1%	254	13.5%	
% of Total	1,548	82.5%	328	17.5%	1,876	100.0%	
Are you ever afraid or scared when you are at home							
No, rarely	1,271	79.2%	262	78.2%	1,533	79.1%	X ² =.183
Sometimes	245	15.3%	54	16.1%	299	15.4%	
Yes, most of the time	88	5.5%	19	5.7%	107	5.5%	
% of Total	1,604	82.7%	335	17.3%	1,939	100.0%	
Are you ever afraid or scared when out in your neighborhood							
No, rarely	1,249	79.2%	256	77.1%	1,505	78.8%	X ² =.918
Sometimes	207	13.1%	50	15.1%	257	13.5%	
Yes, most of the time	122	7.7%	26	7.8%	148	7.7%	
% of Total	1,578	82.6%	332	17.4%	1,910	100.0%	
When you want to go somewhere do you always have a way to get there							
Yes, almost always	1,294	80.6%	273	83.7%	1,567	81.1%	X ² =1.778
Sometimes	251	15.6%	42	12.9%	293	15.2%	
No, almost never	60	3.7%	11	3.4%	71	3.7%	
% of Total	1,605	83.1%	326	16.9%	1,931	100.0%	

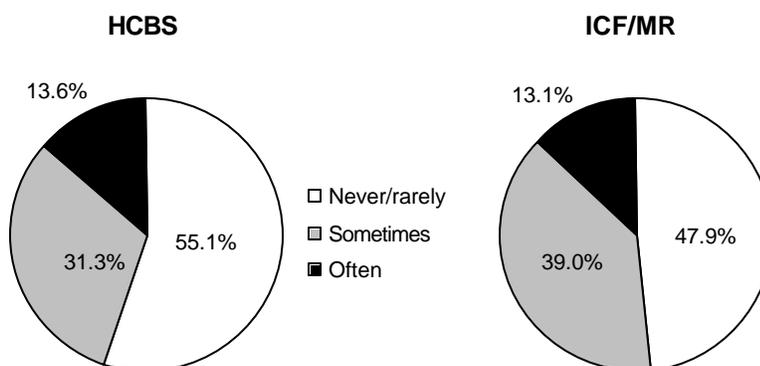
*p<.05

Feeling happy or sad. As part of his interview sample members were asked whether they were in the present feeling happy or sad. (This question was asked twice in reversed order in the interview and served as a consistency check of responses.) At the time of the interview 82.1% of HCBS recipients and 78.8% of ICF/MR residents reported feeling happy, about 5.4% of both groups reported feeling sad with about 12.5% of HCBS recipients and 15.5% of ICF/MR residents indicating that they felt somewhere in-between.

Feelings of loneliness.

When asked whether they ever felt lonely, HCBS recipients were more likely than ICF/MR residents to respond with no or not often (55.1% and 47.9%,

Chart 11. Feelings of Loneliness Among HCBS and ICF/MR Service Recipients in Six States

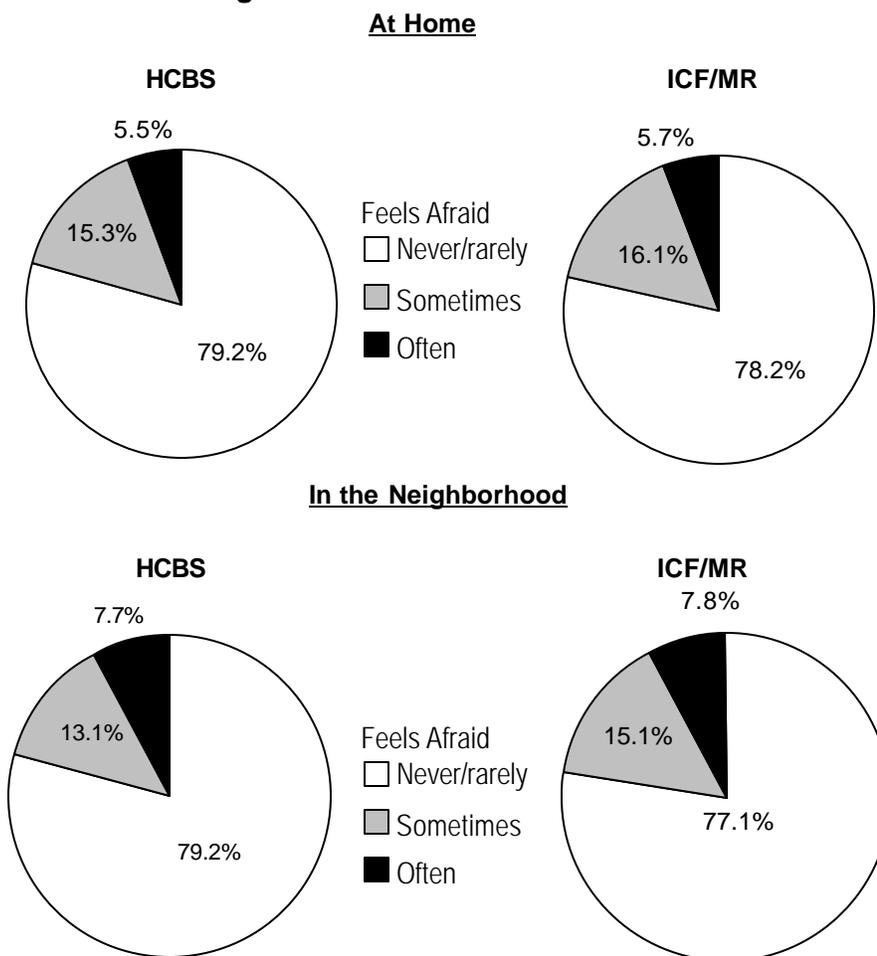


respectively). There were no statistical differences between HCBS recipients and ICF/MR residents in reports that they often felt lonely. ICF/MR recipients were more likely than HCBS recipients to report they sometimes felt lonely (see Chart 11).

Feelings of fear in the home and neighborhood. Substantial majorities of HCBS and ICF/MR said they were never or rarely afraid (or scared) in their home or when they are in their neighborhood (see Chart 12). Overall 79.1% of the sample reported never or rarely being afraid at home with statistically equal reports by HCBS and ICF/MR recipients (79.2% and 78.2%, respectively). About 5.5% of the samples, again in statistically equal proportions, reported they felt afraid most of the time in their home.

Similar reports were obtained about feelings while out in their neighborhood. In statistically equal proportions (79.2% of HCBS and 77.1% of ICF/MR recipients) respondents indicated that they never or rarely felt fear in their neighborhood. About 7.7% of both groups of sample members reported they felt fear most of the time when they were out in their neighborhood (see Chart 12).

Chart 12. Reported Feelings of Fear of HCBS and ICF/MR Recipients in their Home and Neighborhoods



Sense of connectedness. Interviewees were asked whether when they want to go somewhere if they have a way to get where they want to be. About 81.1% of both the HCBS and ICF/MR interviewees responded that they did, always or almost always. About 15% of both groups reported that they sometimes did, with less than 4% (3.7%) indicating that they almost never had a way to get to where they wanted to be.

Indicators of lifestyle quality by home type. Table 16 presents a summary of three lifestyle quality indicators, sense of loneliness, fear and satisfaction with place of residence for HCBS and ICF/MR recipients. These are broken down by the type of home in which the sampled individual lived. All ICF/MR respondents were in congregate/agency-operated homes while HCBS recipients were divided among congregate/agency-operated homes, host families, own homes and family homes.

Feelings of loneliness. Persons in congregate care, whether HCBS or ICF/MR, were most likely to report feelings of loneliness (33.9% sometimes and 17.0% often). Loneliness was also fairly commonly reported by people living in their own homes (34.1% sometimes and 11.9% often). Feelings of loneliness were least often reported by people in host family arrangements (67.7% never or rarely feeling lonely) and people living with family members (60.2% never or rarely feeling lonely).

Ever afraid at home. People residing in congregate/agency housing and people living in their own homes were most likely to report often or sometimes feeling fear at home. This included 23.4% of HCBS and ICF/MR residents in congregate/agency homes and 21.9% of people living in their own home. People in host family (or companion) arrangements least often reported fear at home (10.8%). About 17% of people living with family members reported feelings of fear at home, but they were least often to report they had these feelings often.

Liking their home. All respondents reported high levels of satisfaction with their homes. People in congregate agency homes were most often to report that they often or sometimes did not like where they lived (14.8%). There was no statistical difference in this report for congregate/agency residents in HCBS or ICF/MR funded facilities. People in host family (or companion) homes and people living with family members were least likely to report that they did not or only sometimes like where they lived (3.6% and 3.9%, respectively).

Table 16. Indicators of Basic Lifestyle Quality by Home Type for HCBS and ICF/MR Recipients in Six States

Lifestyle Indicator/Home type	HCBS		ICF/MR		Total		Sig.
	N	%	N	%	N	%	
Ever Feel Lonely							
Congregate/Agency Op.							
No	309	49.8			466	49.2	
Sometimes	193	31.1	157	47.9	321	33.9	
Yes-often	118	19.0	128	39.0	161	17.0	
Host Family							
No	84	67.7	43	13.1	84	67.7	??=8.549*
Sometimes	30	24.2			30	24.2	
Yes-often	10	8.1			10	8.1	
Own Home							
No	222	54.0			222	54.0	
Sometimes	140	34.1			140	34.1	
Yes-often	49	11.9			49	11.9	
Family Home							
No	230	60.2			230	60.2	
Sometimes	118	30.9			118	30.9	
Yes-often	34	8.9			34	8.9	
Ever Afraid at Home							
Congregate/Agency Op.							
No	486	75.7	262	78.2	748	76.6	??=.961
Sometimes	111	17.3	54	16.1	165	16.9	
Yes-often	45	7.0	19	5.7	64	6.6	
Host Family							

No	116	89.2			116	89.2	
Sometimes	7	5.4			7	5.4	
Yes-often	7	5.4			7	5.4	
Own Home							
No	329	78.1			329	78.1	
Sometimes	70	16.6			70	16.6	
Yes-often	22	5.2			22	5.2	
Family Home							
No	331	83.0			331	83.0	
Sometimes	55	13.8			55	13.8	
Yes-often	13	3.3			13	3.3	
Likes Home/Place Lives							
Congregate/Agency Op.							
No	56	8.2	34	9.5	90	8.6	
Sometimes	45	6.6	19	5.3	64	6.1	
Yes-often	584	85.3	304	85.2	888	85.2	?2=1.089
Host Family							
No	2	1.4			2	1.4	
Sometimes	3	2.2			3	2.2	
Yes-often	133	96.4			133	96.4	
Own Home							
No	23	5.3			23	5.3	
Sometimes	34	7.9			34	7.9	
Yes-often	373	86.7			373	86.7	
Family Home							
No	4	.9			4	.9	
Sometimes	13	3.0			13	3.0	
Yes-often	410	96.0			410	96.0	

*p<.05

Indicators of lifestyle quality by homes size. Table 17 presents a summary of three lifestyle quality indicators, sense of loneliness, fear and satisfaction of place of residence by the total number of people with disabilities living in the home. No distinctions are made for HCBS or ICF/MR status. These data include only 5 states because home size was not included in the Alabama data set. As shown there were statistically significant differences in reported loneliness by persons living in homes of different sizes. Specifically people living in settings of 3 or fewer residents were considerably less likely to report they “often” felt lonely (11.0% as compared with 19.6% in larger settings). Differences in feelings of fear within the home did not differ statistically by home size. People in homes of 3 or fewer residents with disabilities were more likely (p<.001) to report they liked where they lived (90.5% as compared with 85.0% of people in paces of 4-6 residents and 82.9% of people in places of 7 or more residents).

Table 17. Indicators of Basic Lifestyle Quality by Size of Home for Adult HCBS and ICF/MR Recipients in Five* States

Lifestyle Indicator	Persons with Disability in Residence								Total N	Total %
	1		2-3		4-6		7+			
	N	%	N	%	N	%	N	%		
Ever Feel Lonely										
No/rarely	325	55.4%	264	56.2%	165	51.7%	89	43.6%	843	53.4% ¹
Sometimes	197	33.6%	155	33.0%	89	27.9%	78	38.2%	519	32.8%
Yes- often	65	11.1%	51	10.9%	65	20.4%	37	18.1%	218	13.8%
Total	587	100.0%	470	100.0%	319	100.0%	204	100.0%	1580	
Ever Afraid at Home										
No/rarely	496	82.0%	378	79.4%	255	76.6%	156	76.5%	1285	79.4% ²
Sometimes	89	14.7%	69	14.5%	54	16.2%	37	18.1%	249	15.4%
Yes- often	20	3.3%	29	6.1%	24	7.2%	11	5.4%	84	5.2%
Total	605	100.0%	476	100.0%	333	100.0%	204	100.0%	1618	
Likes Home/Place Lives										
No	25	4.0%	18	3.7%	24	6.9%	21	10.0%	88	5.3%
In-between	31	5.0%	31	6.4%	28	8.1%	15	7.1%	105	6.3%
Yes	562	90.9%	438	89.9%	294	85.0%	174	82.9%	1468	88.4%
Total	618	100.0%	487	100.0%	346	100.0%	210	100.0%	1661	

Significance tests: ¹ $\chi^2(3)=15.02, p<.001$; ² $\chi^2(3)= 5.87, n.s.$; ³ $\chi^2(3)=15.97, p<.001$

*Home size was not available in individual records for one of the 6 states

Personal and Support Related Choice and Inclusion

Three reliable subscales have been created from NCI surveys to assess choice and inclusion of HCBS and ICF/MR recipients. The scale scores are computed by averaging the values of the individual items comprising each scale. In order for a score to be computed, the person (or a proxy respondent) must have answered a minimum number of questions. All scales have exhibited internal consistency greater than 0.70 (Chronbach's alpha).

Choice and Decision-Making.

The Consumer Survey includes eleven choice items. Two scales are created using the mean of nine items. The first scale, called the Personal Choices sub-domain includes four items. These items indicate whether people choose (or have some input in choosing) in a) people they live with (if not living with family), b) daily schedule, c) how to spend free time, and d) what to buy with spending money. Internal consistency of the Personal Choices scale as measured by Cronbach's alpha was 0.96. The second scale, called the Support-Related Choices sub-domain is composed of five items. These items indicate whether people chose (had some input in choosing, or others chose) the a) place where they live (if not living with family), b) staff who help at home, c) work or day activity, d) staff who help at work, and e) case manager/service coordinator. Internal consistency of the Supports-Related Choices scale was high, with a Cronbach's alpha = 0.92.

Personal Choice

Personal choice and level of ID. Table 18 summarizes personal choice of HCBS and ICF/MR recipients in their daily lives. Personal choice is a composite variable created from 4 areas in which people exercise full, partial or no choice in daily life decisions: 1) the people they live with; 2) their daily schedule; 3) how they spend their free time; and 4) what they buy on their own spending money. An average score of 2.0 would mean that an individual chose by him/herself in all 4 areas; 1.0 would indicate that they participated but were helped in decisions made in all 4 areas; 0.0 would indicate that others made the decisions without their involvement in all 4 areas.

As shown in Table 18, level of intellectual disability (ID) is a strong predictor of the level of personal choice among people participating in both HCBS and ICF/MR programs. The overall mean for persons in the sample was 1.26, with means varying from 1.56 for persons with mild ID to .65 for persons with profound ID. These differences are reflected in the large differences between the mean personal choice scores of HCBS and ICF/MR recipients (1.33 and .95, respectively). As shown graphically in Chart 13, even controlling for level of ID, HCBS recipients at all levels of ID have statistically higher personal choice scores than persons living in ICF/MR. But that program effect, as noted, earlier is substantially related to the within program residential model.

Table 18. Personal Choice * for Adults (18 or Older) with ID/DD Receiving HCBS or ICF/MR Services in Six States

Level of Intellectual Disability	HCBS (N = 2,247) Mean	ICF/MR (N = 567) Mean	Total (N = 2,814) Mean
Mild	1.58	1.43	1.56
Moderate	1.38	1.17	1.35
Severe	1.12	0.94	1.07
Profound	0.73	0.55	0.65
Total	1.33	0.95	1.26

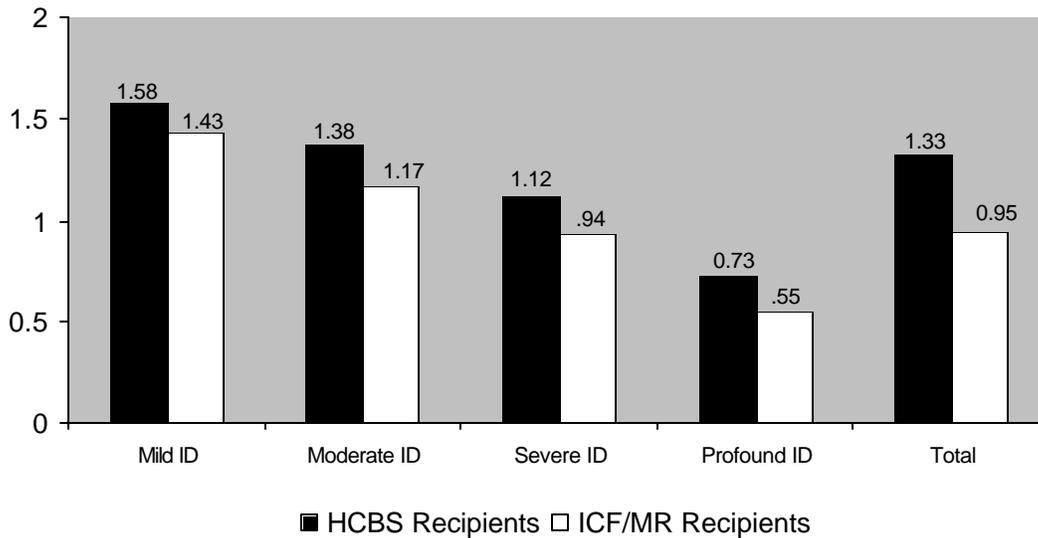
R Squared = .347

Main Effects: Level of Intellectual Disability (F=307.74, p < .001; HCBS vs. ICF/MR (F=56.99, p < .001; HCBS-ICF/MR (F=.265)

1 Mild > moderate, severe and profound; 2 Moderate < Mild > severe and profound; 3 Severe < Mild and moderate, > profound; 4 Profound < Mild, moderate, and severe

* Personal Choice is a composite variable based on interview reports on consumer choice and participation in choosing: 1) the people they live with, 2) their daily schedule, 3) how they spend their free time, and 4) what they buy with their own spending money. Choice is coded as: individual chose by self (2), individual participated in the decision (1), or choice was made by others (0)

Chart 13. Personal Choice Scores* of HCBS and ICF/MR Recipients in Six States by Level of Intellectual Disability



Personal Choice and Size of Home. Table 19 summarizes the combined HCBS and ICF/MR recipients by level of ID and number of people with disabilities living in the sample member’s home. The number of people per home is reported in 4 groups: 1 person, 2-3 people, 4-6 people, and more than 7 people. The sample size in this analysis is reduced because the number of residents in the sample member’s residential settings was not included in one state’s data set. This table shows the strong association between level of ID and personal choice scores. It also shows the substantial association between the number of people with disabilities living in the settings and the degree of personal choice in the lives of sample members. As setting size increases there is a substantial and statistically significant tendency for personal choice to decrease, generally and within the level of ID groupings.

Table 19. Personal Choice* of Adults (18 and Older) with ID/DD Receiving Medicaid HCBS and ICF/MR Services in Five States by Level of Intellectual Disability and Size of Setting

	Level of Intellectual Disability					Sig.
	Mild ¹	Moderate ²	Severe ³	Profound ⁴	Total	
Persons with DD in Home	Mean	Mean	Mean	Mean	Mean	
1 Person ⁵	1.79	1.56	1.26	1.03	1.62	5
2-3 Persons ⁶	1.56	1.39	1.22	0.77	1.31	6
4 - 6 Persons ⁷	1.38	1.24	1.10	0.82	1.20	7
7 or More ⁸	1.36	1.23	0.95	0.65	0.99	8
Total	N=861	N=467	N=354	N=405	N=2,087	1,2,3,4
Mean	1.57	1.36	1.13	0.75	1.29	

Main Effects: Level of Intellectual Disability (F=203.800, p < .001); Size of Residence (F=40.820, p < .001); Level of ID vs. Size of Residence (F=2.289, p < .05); R Squared = .373

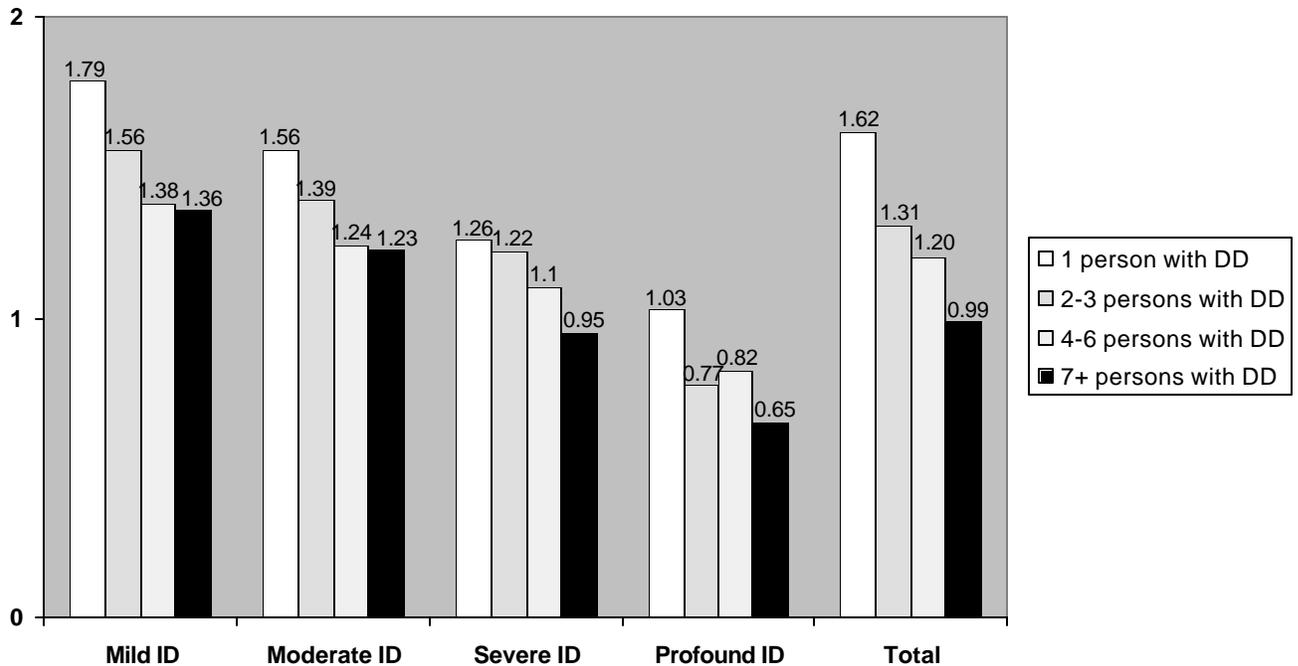
1 Mild > moderate, severe and profound; 2 Mild > moderate > severe and profound; 3 Severe > profound; 4 Profound < mild, moderate, severe

5 1 person home > 2-3, 4-6, and 7+ person homes; 6 2-3 > 1, 4-6, and 7+; 7 4-6 > 1, 2-3, and 7+; 8 7+ < 1, 2-3, and 4-6.

Note: *Personal Choice is a composite variable based on interview reports on consumer full choice or participation in choosing: 1) the people they live with, 2) their daily schedule, 3) how they spend their free time, and 4) what they buy with their own spending money. Choice is coded as: individual chose by self (2), individual participated in the decision (1), or the choice was made by others.

Differences in personal choice scores among persons with mild ID ranged from 1.79 for people in settings of 1 individual with DD to 1.36 for individuals in settings with 7 or more individuals with DD. For persons with moderate ID personal choice scores were 1.56 in settings of 1 person and 1.23 in settings of 7 or more persons. Personal choice scores for persons with severe and profound ID averaged 1.21 and 1.03, respectively, for persons living in a one person setting, as compared with .95 and .65 for persons with severe and profound ID living in places with 7 or more residents. The effect for level of ID was greater than that of setting size ($F=2.29$, $p < .05$). The differences by setting size and level of ID are shown in Chart 14.

Chart 14. Personal Choice Scores for HCBS and ICF/MR Recipients in 5 States by Residential Setting Size and Level of Intellectual Disability



Personal choice and home type by level of ID. Recognizing the effects of the association between level of ID and personal choice scores and also that about one-third of people living in places with 1 or 2 persons were living with family members, an analyses of variance was conducted to examine the effect of residence size within level of ID categories. Table 20 presents the analysis of variance of personal choice by level of ID and residence in 5 states (Indiana, Kentucky, Massachusetts, Oklahoma and Wyoming). It shows that choice was associated with level of ID and residential setting characteristics in many of the comparisons, but that there were modest ($p < .05$)

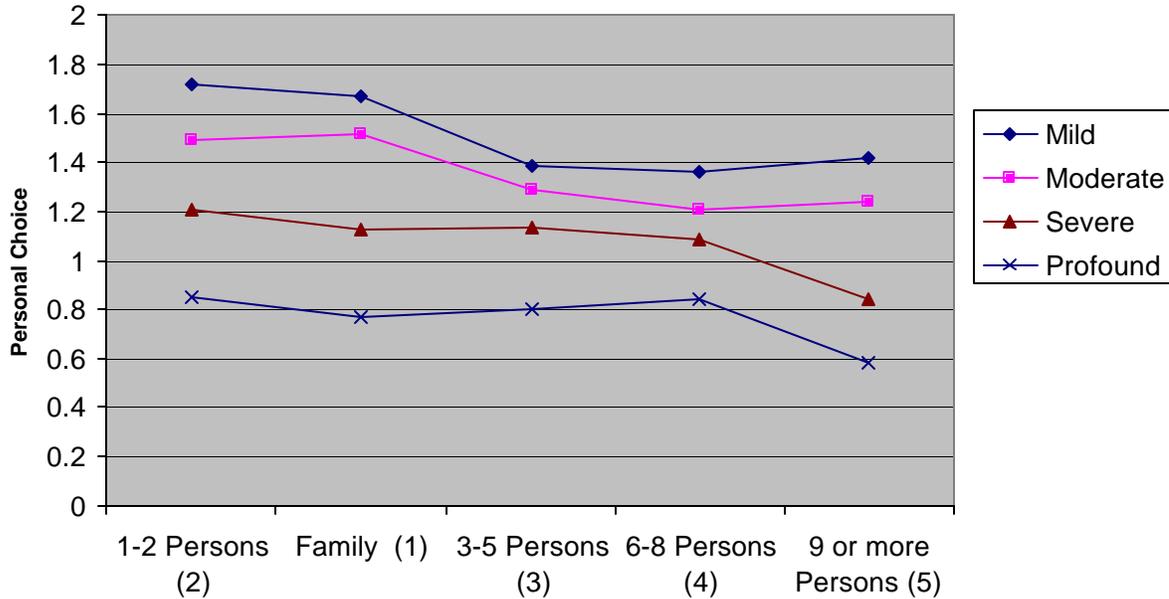
interactions detected as well. Specifically, as has been noted previously, level of ID was consistently associated with choice. For persons with mild and moderate ID, people living in places with 1 or 2 residents away from a family home had the highest rates of personal choice. But in other analyses personal choice was inconsistently associated with home type. For sample members with severe and profound ID the pattern of association showed consistently and significantly less personal choice for persons living in settings of 9 or more residents, but relatively little difference for those in smaller settings of different sizes or in the family home. These patterns are shown graphically in Chart 15.

Table 20. Personal Choice of Adults (18 and Older) Receiving Medicaid HCBS and ICF/MR Services in Five States by Intellectual Level and Setting Size

Persons with DD in Residence	Level of Intellectual Disability					Significance test (Level of ID within size of residence)
	Mild (i)	Moderate (ii)	Severe (iii)	Profound (iv)	Total	
Family (1)	1.67 (n=210)	1.52 (n=169)	1.13 (n=75)	0.77 (n=45)	1.46 (N=499)	i > ii ; iii ; iv ii > iii ; iv iii vs. iv i > ii ; iii ; iv ii > iii ; iv iii > iv
1-2 Persons (2)	1.72 (n=455)	1.49 (n=164)	1.21 (n=99)	0.85 (n=102)	1.51 (N=820)	i > iii ; iv ii > iii ; iv iii > iv
3-5 Persons (3)	1.39 (n=250)	1.29 (n=172)	1.14 (n=133)	0.80 (n=123)	1.21 (N=678)	i > iii ; iv ii > iii ; iv iii > iv
6-8 Persons (4)	1.36 (n=122)	1.21 (n=77)	1.09 (n=70)	0.84 (n=59)	1.17 (N=328)	i > iii ; iv ii > iv iii > iv
9 or more Persons (5)	1.42 (n=27)	1.24 (n=24)	0.84 (n=36)	0.58 (n=111)	0.82 (N=198)	i > iii ; iv ii > iii ; iv iii > iv
Total	1.59 (N=1,064)	1.40 (N=606)	1.12 (N=413)	0.76 (N=440)	1.32 (N=2,523)	i > ii ; iii ; iv ii > iii ; iv iii > iv
Significance test (Size of residence within level of ID)	1 > 3*** 1 > 4*** 1 > 5** 2 > 3*** 2 > 4*** 2 > 5***	1 > 3*** 1 > 4*** 2 > 3*** 2 > 4*** 2 > 5***	2 > 5***	2 > 5** 3 > 5* 4 > 5*	1 > 3*** 1 > 4*** 1 > 5*** 2 > 3*** 2 > 4*** 2 > 5*** 3 > 5*** 4 > 5***	
Main Effects: Level of Intellectual Disability (F=215.620***); Size of Residence (F=22.214***)						
Interaction: Level of ID * Size of Residence (F=4.319)						
Adj. R Squared = .358						

Note: *Personal Choice is a composite variable based on interview reports on consumer full choice or participation in choosing: 1) the people they live with, 2) their daily schedules, 3) how they spend their free time, and 4) what they buy with their own spending money. Choice is coded as: individual chose by self (2), individual participated in decision (1), or choice was made by others.

Chart 15. Patterns of Personal Choice by Level of ID and Residential Setting Type of HCBS and ICF/MR Recipients in Five States



*p<.05; **p<.01; ***p<.001

Personal choice and Type of Home. Table 21 provides a summary of the average Personal Choice scores for sample members from the 6 states by type of residential setting in which they lived. The four type of housing examined were 1) congregate/agency-operated housing, including ICFs/MR, group homes and other staffed group housing, 2) host family settings, also referred as foster, shared living or companion living in which a person shares a home with people who also provide support, 3) own home, including homes owned or rented by an individual(s) or apartment programs with part-time staffing, and 4) people living with family members. In all comparisons, congregate settings offered the lowest levels of personal choice (p<.001 on all comparisons). People living in their own homes reported the highest levels of personal choice with statistically significant differences between comparisons.

Differences between family living in a host family and living with one’s own relatives were negligible, but personal choice was slightly higher (p<.05) for individuals living in the family home as compared with a host family.

Table 21. Average Personal Choice Scores by Type Home for Persons with ID/DD Receiving HCBS and ICF/MR Services in Six States

Type Home

Choice	Congregate (1)	Host Family (2)	Own Home (3)	Family (4)	Significance tests	
<u>Personal Choice</u>					1 < 2 ^{***}	2 < 3 ^{***}
Mean	1.040	1.300	1.575	1.430	1 < 3 ^{***}	2 < 4 [*]
SD	.566	.504	.490	.577	1 < 4 ^{***}	3 > 4 ^{***}

Note: The sample size was 1,590 for “Congregate”, 200 for “Host Family”, 731 for “Own Home”, 651 for “Family” (3,178 in total); Significance based on Bonferroni test: ^{***} p <.001, ^{**} p<.01, ^{*} p <.05 (two-tailed)

Multiple regression analyses of personal choice. Given the substantial number of factors statistically associated with personal choice outcomes, a multiple regression analysis was conducted to examine the relationships between independent variables and support-related choice. The ordinary least-squares (OLS) regression model was employed. Independent variables were ordered in blocks, including a) level of ID, b) health, physical and sensory limitations, c) challenging behavior; d) mental illness/psychiatric conditions, e) autism, f) gender and age, g) home/residential service type, h) HCBS or ICF/MR program participant and i) state.

Table 22 presents the results of the OLS regression according to the blocks of variables identified above. In Table 22 standardized coefficients (β) as well as unstandardized coefficients (β) are shown (with standard errors shown in parenthesis). Standardized coefficients are reported because unstandardized coefficients cannot be compared directly when estimated for arbitrary scales (e.g., in Table 22 level of ID and frequency of health care needed). By rescaling both the independent and dependent variable in terms of their standard deviations, the standardized coefficient indicates the relative importance among the different predictor variables in accounting for variability in the dependent variable in a multiple regression model. The results showed that level of ID had a strong association with individual’s levels of participation in personal choice, accounting for about 32 percent of a total variance ($R^2=.324$, $p<.001$). The medical, physical and sensory limitations block of variables was also strongly associated with personal choice (R^2 change=.009, $p<.001$), with both medical care needs (lower) and mobility (non-ambulatory) having statistically significant associations with personal choice. Challenging behavior, both self-injurious and disruptive, were associated with lower levels of personal choice and together contributed to an R^2 increase of .011 ($p<.001$). There was a minor association between a psychiatric diagnosis and lower personal choice ($p<.05$), but none associated with a diagnosis of autism. Higher age had a minor association with lower choice; gender had none. Residential settings were highly associated with personal choice, specifically people living in host family, own home or family homes all reported higher levels of personal choice ($p<.001$) and together they contributed 6% to the variation in personal choice accounted for by the equation. Living in an ICF/MR was associated with lower choice ($p<.001$) and added .007 to the extent to which variations in choice were accounted for in the regression equation. Finally, in comparison with the reference state, sample members from the other 5 states reported significantly higher personal choice scores.

Altogether nearly half (48%) of the variation in personal choice scores among sample members were accounted for by the variables examined, with level of ID having a particularly strong association. Also notable was the effect of residential setting on

choice once the effects of level of ID, health, physical and sensory indicators, challenging behavior, mental illness and age and been controlled. Once residential setting was controlled, specifically the association of congregate/agency operated housing (whether HCBS or ICF/MR) with lower personal choice, ICF/MR accounted for a small, albeit statistically significant, amount of variance in personal choice scores.

Table 22. Unstandardized and Standardized Coefficients from a Regression of Selected Variables on Personal Choice (N=2,537) for HCBS and ICF/MR Recipients with ID/DD in Six States

Independent	Personal Choice																	
	1		2		3		4		5		6		7		8		9	
	b	β	b	β	b	β	b	β	b	β	b	β	b	β	b	β	b	β
Level of ID	-.282 (.008)	-.569***	-.266 (.009)	-.536***	-.254 (.009)	-.513***	-.258 (.009)	-.521***	-.257 (.009)	-.519***	-.256 (.009)	-.518***	-.229 (.009)	-.462***	-.220 (.009)	-.445***	-.194 (.009)	-.391***
Medical care			-.046 (.010)	-.075***	-.039 (.010)	-.064***	-.036 (.010)	-.060***	-.037 (.010)	-.060***	-.036 (.010)	-.059***	-.017 (.010)	-.028	-.006 (.010)	-.009	-.029 (.010)	-.048**
Mobility ^a			-.089 (.030)	-.051**	-.110 (.030)	-.064***	-.118 (.030)	-.068***	-.122 (.030)	-.070***	-.126 (.030)	-.073***	-.120 (.029)	-.069***	-.119 (.029)	-.069***	-.184 (.027)	-.106***
Vision			-.015 (.020)	-.013	-.005 (.020)	-.004	-.004 (.020)	-.004	-.005 (.020)	-.005	-.004 (.020)	-.003	-.005 (.019)	.005	.003 (.019)	.002	-.011 (.018)	-.009
Self-injury					-.046 (.014)	-.058**	-.044 (.014)	-.056**	-.042 (.014)	-.053**	-.044 (.014)	-.055**	-.040 (.014)	-.050**	-.039 (.014)	-.049**	-.038 (.013)	-.047**
Disruptive behavior					-.032 (.008)	-.071***	-.029 (.008)	-.064***	-.029 (.008)	-.064***	-.029 (.008)	-.066***	-.019 (.008)	-.043*	-.019 (.008)	-.043*	-.024 (.007)	-.053**
Psychiatric D _x							-.053 (.021)	-.042*	-.054 (.021)	-.042*	-.052 (.021)	-.041*	-.021 (.021)	-.017	-.021 (.021)	-.016	-.044 (.020)	-.034*
Autism ^b								-.048 (.041)	-.019	-.054 (.042)	-.022	-.040 (.040)	-.016	-.044 (.040)	-.018	-.082 (.037)	-.033*	
Gender ^c										.020 (.019)	.017	.010 (.018)	.008	.011 (.018)	.009	.022 (.017)	.019	
Age										-.023 (.011)	-.034*	-.004 (.011)	-.005	-.001 (.011)	-.002	.003 (.010)	.005	
Type Home ^d																		
Congregate																		
Host Family													.134 (.038)	.056***	.099 (.039)	.041***	.044 (.037)	.018
Own Home													.343 (.023)	.255***	.334 (.023)	.249***	.331 (.024)	.254***
Family Home													.252 (.027)	.163***	.221 (.027)	.144***	.248 (.026)	.161***
ICF/MR person ^e															-.134 (.024)	-.093***	-.083 (.027)	-.058**
STATE ^f																		
State 1																		
State 2																	.347 (.035)	.270***
State 3																	.666 (.042)	.313***
State 4																	.443 (.034)	.317***
State 5																	.389 (.038)	.238***
State 6																	.569 (.036)	.349***
Intercept	1.865*** (.020)		1.927*** (.030)		1.927*** (.030)		1.945** (.031)		1.947*** (.031)		1.978*** (.038)		1.689*** (.041)		1.690*** (.041)		1.276*** (.048)	
Adjusted R ²	.324		.333		.343		.344		.344		.345		.403		.409		.479	
R ²	.324		.334		.344		.346		.346		.348		.406		.413		.482	
R ² change	.324***		.009***		.011***		.002*		.000		.001		.058***		.007***		.070***	

***p<.001, **p<.01, *p<.05 (two-tailed test)

a. 0=ambulatory, 1= non-ambulatory; b. 0=no, 1=yes; c. 0= male, 1=female; d. Congregate is the reference group for type home variables; e. 0=HCBS, 1=ICF/MR; f. State 1 is the reference group for state dummy variables

*Note: The differences between 2,537 HCBS persons included in this regression and 2,948 persons in the total sample is because sample members were eliminated from the regression if they had a missing value in any one of the variables included. The numbers in parentheses are the standard errors of the b statistic, which is the unstandardized coefficient. β is the standardized coefficient (standardized against the standard error) to reflect the relative importance of the variables in the regression equation.

Support Related Choice

Table 23 summarizes support related choices in the lives of HCBS and ICF/MR recipients with different levels of intellectual disability. Support related choice is a composite variable created from 5 areas in which people may exercise full, partial, or no choice in decisions related to the supports they receive: 1) the place they live (people living with family members had scores averaged across the other 4 areas), 2) staff who help at home, 3) their work or other day activity, 4) staff who help them at work/day activities, and 5) their case manager/service coordinator. For each area a score of 2 was given when an individual had chosen by him/herself, 1 when he/she had participated in a decision, 0 when others made the decisions without the individual's participation.

Support-related choice and level of ID. As shown in Table 23 support related choice varied greatly by level of ID among both HCBS or ICF/MR recipients. Persons with mild ID had on average the highest support-related choice scores both HCBS and ICF/MR recipients with scores decreasing progressively with increasing intellectual impairment ($p < .001$). It was notable, however, that no group exhibited as much choice in service related

Table 23. Support Related Choice * for Adults (18 or Older) with ID/DD Receiving Medicaid HCBS or ICF/MR Services in Six States

Level of Intellectual Disability	HCBS (N = 2,058) Mean	ICF/MR (N = 531) Mean	Total (N = 2,589) Mean	Sig.
Mild	0.97	0.96	0.97	1
Moderate	0.84	0.77	0.83	2
Severe	0.62	0.61	0.62	3
Profound	0.35	0.35	0.35	4
Total	0.79	0.63	0.76	

R Squared = .200

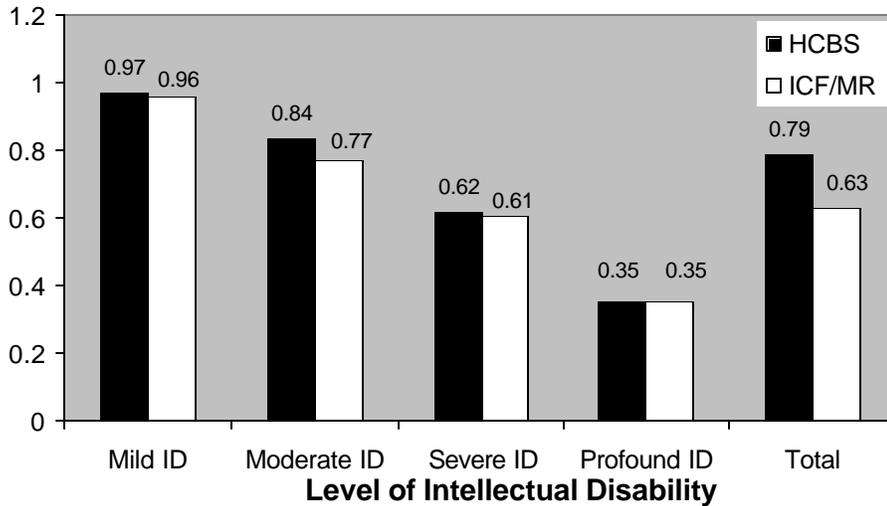
Main Effects: Level of Intellectual Disability ($F=147.50$, $p < .001$); HCBS vs. ICF/MR ($F=1.030$); HCBS-ICF/MR ($F=.354$)

1 Mild > moderate, severe and profound; 2 Moderate < Mild > severe and profound; 3 Severe < Mild and moderate, > profound; 4 Profound < Mild, moderate, and severe

* Support Related Choice is a composite variable based on interview reports on consumer choice and participation in choosing: 1) the place they live (not with family), 2) staff who help them at home, 3) their work or day activity, 4) staff who help them at work / day activity, and 5) their case manager / service coordinator. It is based on the average of the 5 items reported as : choice with help (2), had input into the decision (1), someone else chose (0)

matters as would be viewed as desirable. Even individuals with mild ID had an average score of less than 1, where 1 equals they participated in service related decisions. There was no statistically significant difference between HCBS and ICF/MR recipients in support-related choice once the samples were controlled for level of ID. These differences are summarized in Chart 16.

Chart 16. Differences in Support Related Choice Scores* of HCBS and ICF/MR Recipients with Different Levels of Intellectual Disabilities in Six States



*Average score on 5 support related choice items (place of residence, support staff in home, work or day activity, support staff at work/day activity, case manager/support coordinator. Based on independent choice (2), shared choice (1), someone else's choice (0).

Support-Related Choice, Residential Setting and Level of ID. Table 24 presents the analyses of variance of support related choice, by level of ID and type of residential setting. It shows that support related choice was associated with both level of ID and residential setting characteristics. Specifically the more severe people's level of ID and the more number of persons with ID living in the residence, the less opportunity people had to exercise support related choice in their daily life. People living with 1-2 persons outside their family home had the highest reported support related choice scores followed by people living with family members. This was the same pattern noted with personal choices. Individual comparisons of effects showed that for people with mild ID living in places with 1-2 residents had more support-related choice than persons living with family members or in larger residential settings. But for persons with moderate, severe and profound ID there was less consistent association between support-related choice and residence. One important factor in understanding the lack of consistent association is the strong association between state and support-related choice. As shown subsequently in Table 26, after controlling for a wide range of disability, demographic and setting variables, state variables accounted for 15% of the variability in the support-related choice scores of the sample members.

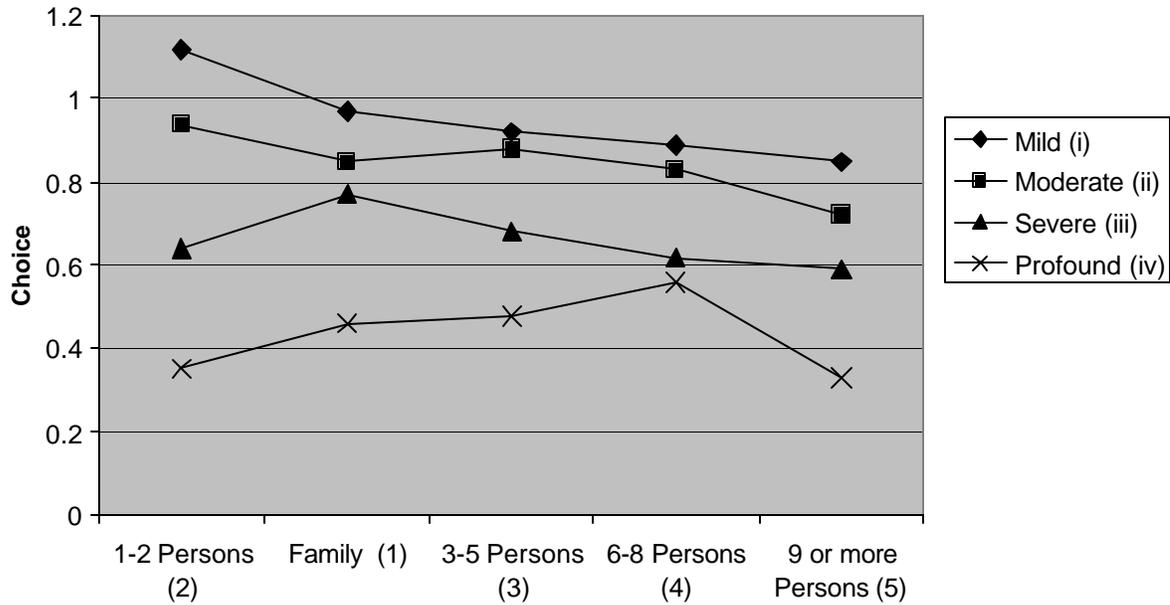
Table 24. Support-Related Choice of Adults (18 and Older) with ID/DD Receiving HCBS and ICF/MR Services in Five States by Level of ID and Size of Setting

Persons with DD in Residence	Level of Intellectual Disability					Significance test (Level of ID within size of residence)
	Mild (i)	Moderate (ii)	Severe (iii)	Profound (iv)	Total	
Family (1)	0.97 (n=156)	0.85 (n=132)	0.77 (n=58)	0.46 (n=32)	0.85 (N=378)	i > iv*** ii > iv**
1-2 Persons (2)	1.12 (n=427)	0.94 (n=157)	0.64 (n=89)	0.35 (n=98)	0.93 (N=771)	i > ii***; iii***; iv*** ii > iii***; iv*** iii > iv
3-5 Persons (3)	0.92 (n=246)	0.88 (n=164)	0.68 (n=130)	0.48 (n=116)	0.79 (N=656)	i > iii***; iv*** ii > iii***; iv*** iii > iv
6-8 Persons (4)	0.89 (n=118)	0.83 (n=74)	0.62 (n=63)	0.56 (n=50)	0.77 (N=305)	i > iii**; iv*** ii > iv
9 or more Persons (5)	0.85 (n=27)	0.72 (n=24)	0.59 (n=35)	0.33 (n=104)	0.50 (N=190)	i > iv*** ii > iv** iii > iv*
Total	1.01 (N=974)	0.88 (N=551)	0.67 (N=375)	0.42 (N=400)	0.82 (N=2,300)	i > ii***; iii***; iv*** ii > iii***; iv*** iii > iv
Significance test (Size of residence within level of ID)	1 < 2* 2 > 3*** 2 > 4*** 2 > 5***	None	None	2 < 4*** 4 > 5***	1 > 5*** 2 > 3*** 2 > 4*** 2 > 5*** 3 > 5*** 4 > 5***	
Main Effects: Level of Intellectual Disability (F(3,2299)=88.313***); Size of Residence (F[4,2299]=3.010*)						
Interaction: Level of ID * Size of Residence (F=3.607*)						
Adj. R Squared = .209						

Note: *Support Choice is a composite variable based on interview reports on consumer full choice or participation in choosing: 1) the place they live (is not with family), 2) staff who help at home, 3) their work or other day activity, 4) staff who help them at work / day activities, and 5) their case manager / service coordinator. It is based on the average of the 5 items reported as: choice with help (2), had input into the decision (1), someone else choice (0).

As with personal choice there was a small, but significant interaction effect between residential setting type and level of ID. As shown in Chart 17 support-related choice appears to decrease consistently as the patterns are not consistent. It appears that size of residence increases among persons with mild and moderate ID. It is notable that among persons with severe and profound ID the patterns are not consistent. It appears that places with 1-2 residents have relatively low support related choices when compared with all but large (9 or more resident) congregate settings. There was notably low support-related choice for persons with severe and profound ID when compared with persons with mild and moderate ID in places with one or two residents.

Chart 17. Patterns of Support-Related Choice by Level of ID and Residential Setting Type of HCBS and ICF/MR Recipients in Six States



Support-Related Choice and Type of Home. Table 27 provides a summary of the average Support-Related Choice scores for sample members from the 6 states by type of residential setting in which they lived. The four type of housing examined were 1) congregate/agency-operated housing, including ICFs/MR, group homes and other staffed group housing, 2) host family settings, also referred as foster, shared living or companion living in which a person shares a home with people who also provide support, 3) own home, including homes owned or rented by an individual(s) or apartment programs with part-time staffing), and 4) people living with family members. In all comparisons, congregate settings appeared to offer the lowest levels of support-related choice ($p < .001$ on all comparisons). People living in their own homes reported the highest levels of support-related choice with statistically significant differences in all comparisons. Differences between living in a host family and living with one’s own relatives were not statistically significant.

Table 25. Average Support-Related Choice Scores by Type Home for Persons with ID/DD Receiving HCBS and ICF/MR Services in Six States

Choice	Type Home				Significance tests
	Congregate (1)	Host Family (2)	Own Home (3)	Family (4)	
Support-related Choice					
Mean	.631	.836	1.575	.958	1 < 2 ^{***} ; 3 ^{***} ; 4 ^{***}
SD	.496	.505	.490	.521	2 < 3 ^{***} ; 3 > 4 ^{***}

Note: The sample size for support-related choice was 1,514 for “Congregate”, 187 for “Host Family”, 698 for “Own Home”, 492 for “Family” (2,891 in total); Significance based on Bonferroni

test: *** $p < .001$, ** $p < .01$, * $p < .05$ (two-tailed)

Multiple Regression Analysis of Support-Related Choice. Given the substantial number of factors statistically associated with support-related choice scores, a multiple regression analysis was conducted to examine the relationships between independent variables and support-related choice. The ordinary least-squares (OLS) regression model was employed. Independent variables were ordered in blocks, including a) level of ID, b) health, physical and sensory limitations, c) challenging behavior; d) mental illness/psychiatric conditions, e) autism, f) gender and age, g) home/residential service type, h) HCBS or ICF/MR program participant and i) state.

Table 26 presents the results of the OLS regression according to the blocks of variables identified above. In Table 26 standardized coefficients (β) as well as unstandardized coefficients (β) are shown (with standard errors shown in parentheses). Standardized coefficients are reported because unstandardized coefficients cannot be compared directly when estimated for arbitrary scales (e.g. in Table 26 level of ID and frequency of health care needed). By rescaling both the independent and dependent variable in terms of their standard deviations, the standardized coefficient indicates the relative importance among the different predictor variables in accounting for variability in the dependent variable in a multiple regression model. The results indicated that level of ID had a strong association with individuals' levels of participation in support-related decisions, accounting for about 21 percent of a total variance ($R^2 = .208$, $p < .001$). The second block of variables, medical, physical and sensory limitation had a modest association with participation in life decisions ($p < .05$; R^2 change = .004), with mobility and health care needs having a modest association with participation. Both self-injurious behavior and disruptive behavior were independently associated with lower levels of participation and together contributed to an increased R^2 (.005, $p < .001$). Having a psychiatric diagnosis or having autism had no significant association with and made no contribution to accounting for variation in participation in support-related choices. Neither age nor gender was associated with variations in support-related choice, although small, statistically insignificant tendencies for choice to be greater for males and younger persons contributed a small bit (.002) to the overall R^2 . As suggested by Table 26, in comparison with congregate care settings, host family, own home and family home settings all had statistically significant associations with greater participation. Together they contributed .024 to the overall variations in participation scores accounted for by the regression. Once home type was entered, ICF/MR status had no association with support-related choice and contributed nothing to accounting for variations in it. In comparison with the reference state (state 1), sample members from other states had significantly higher personal choice scores ($p < .001$ for all 5 other states) and together they added .148 to the ability to account for variation in the degree of participation in important support-related decisions. While there is no doubt that different states have different cultures and different expectations for supporting choice and participation, this is an exceptionally strong state effect that suggested significant cultural and/or policy differences. Overall, the variables included in the regression analysis accounted for 39% of the variation in the participation in support-related choice scores of 2,537 individuals in the regression sample.

Table 26. Unstandardized and Standardized Coefficients from the Regression of Selected Variables Support Related Choice (N=2,537) for HCBS and ICF/MR Recipients with ID/DD in Six States

Independent	Support-Related Choice																	
	1		2		3		4		5		6		7		8		9	
	<i>b</i>	β	<i>b</i>	β	<i>b</i>	β	<i>b</i>	β	<i>b</i>	β	<i>b</i>	β	<i>b</i>	β	<i>b</i>	β	<i>b</i>	β
Level of ID	-.201 (.008)	-.456***	-.202 (.009)	-.458***	-.194 (.009)	-.440***	-.196 (.009)	-.445***	-.195 (.009)	-.443***	-.195 (.009)	-.442***	-.180 (.009)	-.409***	-.181 (.009)	-.410***	-.134 (.009)	-.303***
Medical care			-.021 (.010)	-.039*	-.016 (.010)	-.030	-.015 (.010)	-.028	-.015 (.010)	-.029	-.015 (.010)	-.029	-.003 (.010)	-.006	-.004 (.011)	-.007	-.018 (.010)	-.034
Mobility ^a			.081 (.031)	.051**	.067 (.031)	.043*	.064 (.031)	.041*	.062 (.031)	.040*	.058 (.031)	.037	.062 (.031)	.039*	.062 (.031)	.039*	.003 (.028)	.002
Vision			-.028 (.020)	-.026	-.022 (.020)	-.021	-.022 (.020)	-.021	-.023 (.020)	-.021	-.021 (.020)	-.020	-.016 (.020)	-.015	-.016 (.020)	-.015	-.028 (.018)	-.026
Self-injury					-.033 (.014)	-.047*	-.032 (.014)	-.045*	-.031 (.015)	-.044*	-.033 (.015)	-.047*	-.031 (.014)	-.044*	-.031 (.014)	-.044*	-.028 (.013)	-.040*
Disruptive behavior					-.018 (.008)	-.046*	-.017 (.008)	-.042*	-.017 (.008)	-.042*	-.017 (.008)	-.043*	-.011 (.008)	-.028	-.011 (.008)	-.028	-.018 (.007)	-.045*
Mental illness/psychiatric diagnosis ^b							-.025 (.021)	-.022	-.025 (.021)	-.023	-.025 (.021)	-.022	-.009 (.021)	-.008	-.009 (.021)	-.008	-.038 (.019)	-.034
Autism ^b									-.019 (.041)	-.009	-.018 (.041)	-.008	-.011 (.041)	-.005	-.011 (.041)	-.005	-.075 (.037)	-.034*
Gender ^c									.036 (.019)	.035	.030 (.019)	.029	.030 (.019)	.029	.030 (.017)	.029	.032 (.017)	.031
Age									-.012 (.011)	-.020	-.003 (.011)	-.005	-.003 (.011)	-.005	-.003 (.011)	-.005	-.012 (.010)	-.020
Type Home ^d																		
Congregate																		
Host Family													.123 (.040)	.058**	.124 (.040)	.059**	.082 (.037)	.038*
Own Home													.190 (.023)	.160***	.190 (.023)	.160***	.220 (.024)	.186***
Family Home													.130 (.030)	.088***	.131 (.030)	.089***	.118 (.028)	.079***
ICF/MR person ^e															.005 (.025)	.004	-.046 (.027)	-.037
STATE ^f																		
State 1																		
State 2																	.528 (.035)	.455***
State 3																	.712 (.041)	.385***
State 4																	.413 (.034)	.330***
State 5																	.256 (.038)	.179***
State 6																	.709 (.036)	.489***
Intercept	1.200*** (.020)		1.255*** (.031)		1.254*** (.031)		1.263*** (.032)		1.264*** (.032)		1.268*** (.038)		1.112*** (.043)		1.112*** (.043)		.645*** (.048)	
Adjusted R ²	.208		.210		.215		.215		.215		.216		.238		.237		.385	
R ²	.208		.212		.217		.217		.217		.219		.242		.242		.390	
R ² change	.208***		.004*		.005***		.000		.000		.002		.023***		.000		.148***	

***p<.001, **p<.01, *p<.05 (two-tailed test)

a. 0=ambulatory, 1= non-ambulatory; b. 0=no, 1=yes; c. 0=male, 1=female; d. Congregate is the reference group for type home variables; e. 0=HCBS, 1=ICF/MR; f. State 1 is the reference group for state dummy variables

*Note: The differences between 2,537 HCBS persons included in this regression and 2,948 in the total sample is because sample members were eliminated from the regression if they had a missing value in any one of the variables included. The numbers in parentheses are the standard errors of the b statistic, which is the unstandardized coefficient. β is the standardized coefficient (standardized against the standard error) to reflect the relative importance of the variables in the regression equation.

Community Inclusion

Table 27 summarizes community inclusion of HCBS and ICF/MR recipients. Community inclusion is a composite variable created from reported participation in general areas of community life: 1) shopping, 2) errands and appointments, 3) out-of-home entertainment, 4) eating out, 5) religious services, 6) community clubs, groups or organizations, and 7) community exercise and sporting activities. Inclusion in these activities was coded as: participates (2) or does not participate (0), except for exercise and sports which also included a code (1) for non-integrated activities. The internal reliability of the Community Inclusion Scale has been measured at 0.76 (Cronbach's alpha). The questions in this scale make no distinctions for a period of time in which the participation occurred nor obtained any indication of frequency. As a result relatively little variation was noted within the sample by level of ID, HCBS vs. ICF/MR, or size of home. Despite limitations in the distribution of community inclusion score, level of ID was associated with community inclusion. However, statistically significant differences were detected only between persons with profound ID and the three other groupings (mild, moderate and severe), which were not different from each other. Within level of ID groupings, ICF/MR residents reported higher community inclusion than HCBS recipients. While the community inclusion scores indicated that large percentages of people receiving HCBS and ICF/MR had experienced a wide range of community activities, without a specified time frame and frequency count within that time frame the value of these data were quite limited. This was unfortunate given the importance of the community inclusion outcome.

Table 27. Community Inclusion * of Adults (18 or Older) with ID/DD Receiving Medicaid HCBS or ICF/MR Services in Six States

Level of Intellectual Disability	HCBS (N = 2,267) Mean	ICF/MR (N = 568) Mean	Total (N = 2,835) Mean	Sig.
Mild	1.52	1.58	1.53	1
Moderate	1.53	1.58	1.54	2
Severe	1.50	1.53	1.49	3
Profound	1.39	1.39	1.39	4
Total	1.50	1.49	1.50	

R Squared = .030

Main Effects: Level of Intellectual Disability (F=26.11, p < .001; HCBS vs. ICF/MR (F=4.665, p < .05; HCBS-ICF/MR (F=.960)

1 Mild > profound; 2 Moderate > profound; 3 Severe > profound; 4 Profound < Mild, moderate, and severe

* Community Inclusion is a composite variable based on interview reports on consumer choice and participation in choosing: 1) shopping, 2) errands and appointments, 3) out of home entertainment, 4) eating out, 5) religious services, 6) community clubs, social groups or organizations, and 7) community exercise and sporting activities. Community inclusion is coded as: participates (2), does not participate (0), except for exercise that codes non-integrated exercises (1).

variation was noted within the sample by level of ID, HCBS vs. ICF/MR, or size of home. Despite limitations in the distribution of community inclusion score, level of ID was associated with community inclusion. However, statistically significant differences were detected only between persons with profound ID and the three other groupings (mild, moderate and severe), which were not different from each other. Within level of ID groupings, ICF/MR residents reported higher community inclusion than HCBS recipients. While the community inclusion scores indicated that large percentages of people receiving HCBS and ICF/MR had experienced a wide range of community activities, without a specified time frame and frequency count within that time frame the value of these data were quite limited. This was unfortunate given the importance of the community inclusion outcome.

Autism and Individual Outcomes

As part of the interview process agency staff members were asked to indicate whether an individual sample member had an autism diagnosis noted in his/her records. Altogether there were 172 sample members who were reported to have autism.

Autism and support related choice. There were 2,515 individuals in the sample who had complete data on the presence of a diagnosis of autism in records (yes/no), level of intellectual disability and the support related choice scale. These included 158 individuals diagnosed with autism (6.3%) and 2,357 individuals who were not diagnosed with autism. Table 29 summarizes findings on the association of support related choice with autism within categories of intellectual disability, with persons indicated to have no intellectual disability included in the “mild” category. There was a statistically significant lower overall participation in support related choice by persons with autism than by persons without autism. The average scale score for persons with autism was .58 and for persons without autism and .77 for persons without ($p < .001$). As noted earlier, however, there was a strong association between level of ID and support related choice, with choice diminishing within each successively lower level of ID ($p < .001$). Controlling for level of ID there was not statistically significant difference in the support-related choice of persons with and without autism. There was, however, an interaction effect which showed the score on the support related choice scale for individuals with autism was consistently, but less strongly associated with level of ID than for individuals who did not have an autism diagnosis.

Table 29. Support Related Choice of Individuals with ID/DD Receiving HCBS and ICF/MR Services in Six States by Level of Intellectual Disability and Autism

Autism	Level of Intellectual Disability				Total
	Mild	Moderate	Severe	Profound	
No Autism	.97	.84	.63	.34	.77
Has Autism	.90	.65	.5	.46	.58
Total	.97	.83	.61	.35	.76

Effects: Level of ID ($F[3,2515]=30.091^{***}$); Autism ($F[1,2515]=2.483$); Level of ID * Autism ($F[3,2515]=2.640$)

Significance Test: *Level of ID:* Mild > Moderate^{***}; Mild > Severe^{***}; Mild > Profound^{***}; Moderate > Severe^{***}; Moderate > Profound^{***}; Severe > Profound^{***}

Autism: No > Yes^{***}

Note: The sample size is 1,032 for those with mild disability, 592 for those with moderate disability, 403 for those with severe disability, and 488 for those with profound disability, while 2,357 for those with no autism and 158 for those with autism. Significance test is based on Bonferroni method.

^{***} $p < .001$, ^{**} $p < .01$, ^{*} $p < .05$ (two-tailed)

Autism and personal choices. There were 2,739 individuals in the sample who had complete data on the presence of a diagnosis of autism in records, level of intellectual disability and the personal daily choice scale. These included 167 (6.1%) individuals diagnosed with autism and 2,572 individuals who were not diagnosed with autism. Table 28 summarizes findings on the association of personal daily choice with autism within categories of intellectual disability (persons indicated not to have an intellectual disability diagnosis subsumed in the “mild” category). As shown there was a statistically significant lower overall participation in personal daily choices by persons with autism than by persons without autism. The average scale score for persons with autism was 1.03 and for persons without autism and 1.27 for persons without ($p < .001$). The strong inverse relationship between level of ID and personal daily choice was noted ($p < .001$). Controlling for level of ID there was a modestly lower, statistically significant difference in personal daily choice of persons with autism. There was also an interaction effect which showed personal daily choice ratings for individuals with autism to be consistently, but less strongly associated with level of ID than for individuals who did not have autism.

Table 28. Personal Daily Decisions by Persons with ID/DD Receiving HCBS and ICF/MR Services in Six States by Level of Intellectual Disability and Autism

Autism	Level of Intellectual Disability				Total
	Mild Mean	Moderate Mean	Severe Mean	Profound Mean	
No Autism	1.56	1.37	1.08	.64	1.27
Has Autism	1.39	1.08	.98	.82	1.03
Total	1.56	1.35	1.06	.66	1.26

Effects: Level of ID ($F[3,2739]=58.835^{***}$); Autism ($F[1,2739]=5.336^*$); Level of ID x Autism ($F[3,2739]=6.274^{***}$)

Significance Tests: *Level of ID:* Mild > Moderate^{***}; Mild > Severe^{***}; Mild > Profound^{***}; Moderate > Severe^{***}; Moderate > Profound^{***}; Severe > Profound^{***}

Autism: No > Yes^{***}

Note: The sample size is 1,123 for those with mild disability, 648 for those with moderate disability, 441 for those with severe disability, and 527 for those with profound disability, while 2,572 for those with no autism and 167 for those with autism. Significance test is based on Bonferroni method.
 $p < .05$; $p < .01$; $p < .001$ (two-tailed)

Autism and community inclusion. There were 2,772 individuals in the sample who had complete data on the presence of a diagnosis of autism in records (yes/no), level of intellectual disability and the Community Inclusion subscale. These included 172 (6.2%) individuals diagnosed with autism and 2,600 individuals who were not diagnosed with autism. Table 30 summarizes findings on the association of Community Inclusion subscale “scores” for persons with and without with autism within categories

of intellectual disability (persons indicated not to have an intellectual disability diagnosis included in the “mild” category). As shown community inclusion was lower for persons with profound ID than for persons in the mild, moderate and severe levels of ID ($p < .001$) and lower for persons with severe ID than for persons with moderate ID ($p < .05$). There were no differences between persons with and without an autism diagnosis and there were no interactions between level of ID and autism in the reported degree of community inclusion. As noted earlier, however, the Community Inclusion subscale did not include elements of frequency or of a relatively short, well-defined reporting period, so that overall variation in reported community inclusion was minimized.

Table 30. Community Inclusion of Individuals with ID/DD Receiving HCBS and ICF/MR Financed Services in Six States by Intellectual Level and Autism

Autism	Level of Intellectual Disability				Total Mean
	Mild Mean	Moderate Mean	Severe Mean	Profound Mean	
No	1.53	1.54	1.49	1.39	1.50
Yes	1.55	1.60	1.49	1.36	1.48
Total	1.53	1.54	1.49	1.39	1.50

Effects: Level of ID ($F[3,2772]=9.729^{***}$); Autism ($F[1,2772]=.105$); Level of ID x Autism ($F[3,2772]=.415$)

Significance Tests: *Level of ID:* Mild > Profound^{***}; Moderate > Severe^{*}; Moderate > Profound^{***}; Severe > Profound^{***}; *Autism:* No significant differences were found between groups with and without autism

Note: The sample size is 1,132 for those with mild disability, 662 for those with moderate disability, 449 for those with severe disability, and 529 for those with profound disability, while 2,600 for those with no autism and 172 for those with autism. Significance test is based on Bonferroni method.

* $p < .05$; ** $p < .01$; *** $p < .001$ (two-tailed)

Dual Diagnoses and Individual Outcomes

In the interview process agency staff members were asked to indicate whether an individual sample member had a “mental illness or a psychiatric diagnosis” noted in his/her records. Altogether there were 902 (31.2%) sample members who were reported to have a psychiatric diagnosis as well as an intellectual disability (“dual diagnosis). There were 1,989 sample members who did not have psychiatric diagnoses.

Dual diagnoses and support related choice. There were 2,542 individuals in the sample who had complete data on the presence of a dual diagnosis of psychiatric and intellectual disability in their records, level of intellectual disability and the support

related choice scale. These included 826 (32.5%) individuals with a psychiatric diagnosis and 2,357 individuals with none. Table 31 summarizes findings on the association of Support Related Choice subscale and psychiatric diagnosis within categories of intellectual disability (persons indicated to have no intellectual disability were included in the “mild” category). As shown there was a statistically significant lower overall participation in support related choice by level of ID, but not by the presence of a psychiatric diagnosis. Specifically, controlling for level of ID, persons with psychiatric diagnoses were no more or no less likely to make or participate in support related choices.

Table 31. Support Related Choice by Persons with ID/DD Receiving HCBS and ICF/MR Services in Six States by Level of Intellectual Disability and Presence of Dual Diagnosis

Psychiatric Diagnosis	Level of Intellectual Disability				Total (Row)
	Mild	Moderate	Severe	Profound	
No Dual Diagnosis	.99	.86	.62	.35	.75
Has Dual Diagnosis	.93	.76	.60	.38	.78
Total	.97	.83	.61	.35	.76

Effects: Level of ID ($F[3,2542]=137.484^{***}$); Mental illness ($F[1,2542]=2.526$); Level of ID Mental illness ($F[3,2542]=1.354$)

Significance Tests:
Level of ID: Mild > Moderate^{***}; Mild > Severe^{***}; Mild > Profound^{***}; Moderate > Severe^{***}; Moderate > Profound^{***}; Severe > Profound^{***}
Dual Diagnosis: No significant differences were found between groups with and without dual diagnosis

Note: The sample size is 1,043 for those with mild disability, 603 for those with moderate disability, 407 for those with severe disability, and 489 for those with profound disability, while 1,716 for those with no mental illness and 826 for those with mental illness. Significance test is based on Bonferroni method. * p <.05; ** p<.01; *** p <.001 (two-tailed),

Dual diagnoses and personal daily decisions. There were 2,542 sample members who had complete data on the presence of a dual diagnosis, level of intellectual disability and Personal Choice subscale scores. These included 826 individuals (32.5%) with a psychiatric diagnosis indicated in their records. Table 32 summarizes findings on the association between the presence of a psychiatric diagnosis and the “scores” on the Personal Choice subscale. While the overall means of daily decision making by persons with and without psychiatric diagnoses were not statistically different (1.27 and 1.25, respectively), within the different levels of ID, persons with dual intellectual and psychiatric disabilities reported significantly less

control over their daily decisions ($p < .001$). As with other outcomes, less severe ID was associated with greater participation in decision-making. Therefore, the consistently lower amounts of decision making by persons with dual diagnosis within levels of ID, but equal amounts of overall decision-making, reflects the higher rates of dual diagnosis among persons with mild and moderate ID.

Table 32. Personal Choice by Persons with ID/DD Receiving HCBS and ICF/MR Services in Six States by Level of Intellectual Disability and Presence of Dual Diagnosis

Dual Diagnosis	Level of Intellectual Disability				Total (Row)
	Mild	Moderate	Severe	Profound	
No	1.60	1.39	1.06	.68	1.25
Yes	1.48	1.27	1.06	.55	1.27
Total	1.55	1.35	1.06	.65	1.25

Effects: Level of ID ($F[3,2765]=321.159^{***}$); Dual Diagnosis ($F[1,2765]=15.637^{***}$); Level of ID Dual Diagnosis ($F[3,2765]=1.625$)

Significance Test:
Level of ID: Mild > Moderate^{***}; Mild > Severe^{***}; Mild > Profound^{***}; Moderate > Severe^{***}; Moderate > Profound^{***}; Severe > Profound^{***}
Dual Diagnosis: No significant differences were found between groups with and without dual diagnosis

Note: The sample size is 1,133 for those with mild disability, 659 for those with moderate disability, 444 for those with severe disability, and 529 for those with profound disability, while 1,893 for those with no dual diagnosis and 872 for those with dual diagnosis. Significance test is based on Bonferroni method.
 $p < .05$; $p < .01$; $p < .001$ (two-tailed)

Dual diagnosis and community inclusion. There were 2,799 individuals in the sample who had complete data on the presence of a diagnosis of psychiatric disability in records, level of intellectual disability and the Community Inclusion subscale score. These included 876 individuals (31.3%) with psychiatric diagnoses and 1,923 individuals without a psychiatric diagnosis in their records. Table 33 summarizes findings on the association of community inclusion “scores” for persons with and without dual diagnosis within categories of intellectual disability. As shown community inclusion was lower for persons with profound ID than for persons in the mild, moderate and severe levels of ID ($p < .001$) and lower for persons with severe ID than for persons with moderate ID ($p < .05$). Controlling for level of ID, there was a small tendency for persons with dual diagnosis have to lower Community Inclusion subscale scores than persons without dual diagnosis. Again, however, the Community Inclusion scale did not include elements of frequency that might have better measured overall variation in community inclusion of sample members.

Table 33. Community Inclusion of Persons with ID/DD Receiving HCBS and ICF/MR Services in Six States by Level of Intellectual Disability and Presence of Psychiatric Diagnosis

Dual Diagnosis	Level of Intellectual Disability				Total
	Mild	Moderate	Severe	Profound	
No Dual Diagnosis	1.56	1.56	1.49	1.40	1.51
Has Dual Diagnosis	1.49	1.51	1.49	1.35	1.48
Total	1.53	1.54	1.49	1.39	1.50

Effects: Level of ID ($F(3,2799)=18.591^{***}$); Mental illness ($F(1,2799)=5.993^*$); Level of ID * Mental illness ($F(3,2799)=.933$)

Significance Test
Level of ID: Mild > Profound^{***}; Moderate > Severe^{*}; Moderate > Profound^{***}; Severe > Profound^{***}
Mental illness: No significant differences were found between groups with and without mental illness

Note: The sample size is 1,143 for those with mild disability, 673 for those with moderate disability, 452 for those with severe disability, and 531 for those with profound disability, while 1,923 for those with no dual diagnosis and 876 for those with dual diagnosis. Significance test is based on Bonferroni method.

* $p < .05$; ** $p < .01$; *** $p < .001$ (two-tailed)

Freedom in Daily Life

Table 34 presents a summary of responses regarding aspects of freedom in the daily lives of HCBS and ICF/MR recipients. The statistics are presented for HCBS, ICF/MR and combined recipients. Although as we have noted such aspects of freedom in daily living are highly associated with level of intellectual disability and HCBS and ICF/MR program participants differ notably in level of intellectual disability. At the same time the ADA and other sources of national commitment have not distinguished commitments made to people with disability as being made primarily to persons with less severe disability. What is more while obviously more challenging (or at least level often achieved), it is evident from this and other research that people with severe and profound intellectual disability can be and are being supported to exercise the basic freedoms outline in Table 34.

Table 34. Aspects of Freedom in Daily Lives of HCBS and ICF/MR Recipients in Six States

Question & Response	HCBS		ICF/MR		Total		Sig.
	N	%	N	%	N	%	
Do you choose what to buy with your spending money							
Person decides without help	1,248	53.6%	219	37.9%	1,467	50.4%	X ² =45.608 ***
Person had some input or help	825	35.4%	271	46.9%	1,096	37.7%	
Someone else chooses	257	11.0%	88	15.2%	345	11.9%	
% of Total	2,330	80.1%	578	19.9%	2,908	100.0%	
Who decides how you spend your free time							
Person decides on own	1,484	63.9%	250	43.3%	1,734	59.8%	X ² =123.545 ***
Person has help in deciding	639	27.5%	195	33.7%	834	28.8%	
Someone else decides	199	8.6%	133	23.0%	332	11.4%	
% of Total	2,322	80.1%	578	19.9%	2,900	100.0%	
Who decides your daily schedule e.g. getting up, going to sleep							
Person decides on own	1,226	52.6%	152	26.3%	1,378	47.4%	X ² =208.595 ***
Person has help in deciding	765	32.8%	201	34.8%	966	33.2%	
Someone else decides	339	14.5%	224	38.8%	563	19.4%	
% of Total	2,330	80.2%	577	19.8%	2,907	100.0%	

*** p < .001

Freedom in using spending money. Half (50.4%) of the members of the HCBS and ICF/MR samples reported or were reported to be able to choose without involvement of others what would be purchased with their own spending money. Another 37.7% reported or were reported to have partial participation in the decisions about how spending money was used. Notable differences existed between HCBS and ICF/MR recipients in the use of one's own spending money: 53.6% of HCBS recipients being able to make their own choices and compared with 37.9% of ICF/MR recipients. Conversely, for 11.0% of HCBS recipients and 19.9% of ICF/MR recipients other people made all decisions about how their personal money was used.

Freedom in use of spare time. Overall 59.8% of HCBS and ICF/MR recipients reported or were reported as being able to decide on their own how to use their own spare time. HCBS recipients were considerably more likely to be able to decide on their own about the use of free time than were ICF/MR residents (63.9% and 43.3%, respectively). They were also much less likely to have these decisions made by others without their participation (8.6% and 23.0%, respectively).

Freedom to schedule daily routines. Of the total sample, 47.4% reported or were reported to be able to decide on their own their daily schedules for going to bed and what to eat. There were, however, large differences between HCBS and ICF/MR recipients, with 52.6% of HCBS recipients controlling the daily schedules on their own as

compared with 26.3% of ICF/MR residents.

Freedom to use the phone. High percentages of both HCBS and ICF/MR recipients reported or were reported to be able to use the telephone whenever they chose (90.1% and 84.8%, respectively). There was, however, a significantly higher proportion of people facing restrictions on telephone use in ICFs/MR than in HCBS (15.3% and 9.9%, respectively).

Participation in Self-Advocacy Activities

Table 35 summarizes responses to a question about whether sample members in HCBS and ICF/MR programs had ever participated in self-advocacy groups, meetings, conferences or events. It was explained to interviewees who were not sure what a self-advocacy group was that, “A self-advocacy group is whether people meet together to talk about things in their lives that are important to them.” An estimated 27.6% of HCBS and ICF/MR recipients had attended a self-advocacy function and 7.3% had turned down an opportunity to participate. Comparing HCBS and ICF/MR program participants demonstrated no statistically significant differences in participation in self-advocacy functions. However, among sample members with severe or profound ID a slightly higher proportion of ICF/MR recipients had participated in self-advocacy group or event than had HCBS recipients ($p < .05$).

Table 35. Differential Participation in/Access to Self Advocacy for Persons Receiving HCBS and ICF/MR Services by Level of Intellectual Disability in Six States

Self-Advocacy Participation	Level of Intellectual Disability								
	Mild/Moderate			Severe/Profound			Total		
	HCBS	ICF/MR	Total	HCBS	ICF/MR	Total	HCBS	ICF/MR	Total
No	791 (60.2)	115 (57.2)	906 (59.8)	379 (75.5)	222 (75.5)	601 (75.5)	1,170 (64.4)	337 (68.1)	1,507 (65.2)
Had opportunity but chose not to	104 (7.9)	17 (8.5)	121 (8.0)	38 (7.6)	9 (3.1)	47 (5.9)	142 (7.8)	26 (8.0)	168 (7.3)
Yes	420 (31.9)	69 (34.3)	489 (32.3)	85 (16.9)	63 (21.4)	148 (18.6)	505 (27.8)	132 (26.7)	637 (27.6)
Total	1,315 (86.7)	201 (13.3)	1,516 (100.0)	502 (63.1)	294 (36.9)	796 (100.0)	1,817 (78.6)	495 (21.4)	2,312 (100.0)
χ^2 (df=2)	.731			8.399*			4.507		

Note: Percentages are in parentheses. * $p < .05$; ** $p < .01$; *** $p < .001$ (two-tailed)

Perceptions of Needed Services

Table 36 compares responses from individual sample members and proxy respondents to a question asking whether sample members were receiving the services that they currently needed. As would be expected among sample members with mild or moderate ID (or no ID) there was a much higher rate of direct sample member response (75.4%) than among sample members with severe or profound ID (14.5%). In general the reports of the individual sample members (“consumer”) and proxy respondents about whether sample members were receiving the services they need were: a) positive with 84.9% indicating “yes”, and b) generally similar in the reports “consumer” respondents and “proxy” respondents. There was within the breakdown by mild/moderate and severe/profound ID groupings, a small, but consistent tendency for proxy respondents to more often report a need for additional services. The difference between consumers and other respondents was about 5%-6% in both groupings (although it was statistically significant difference ($p < .01$) in only the mild/moderate group). Among all sample members there was no statistical difference between consumers and proxy respondents in the tendency to perceive a need for additional services.

Table 36. Persons Reported to be Receiving Needed Services: Reports by Persons with ID/DD and Proxies by Level of Intellectual Disability of Sample Members in Six States

Receiving Needed Services	Level of Intellectual Disability								
	Mild/Moderate			Severe/Profound			Total		
	Consumer	Proxy	Total	Consumer	Proxy	Total	Consumer	Proxy	Total
No (%)	78 (5.7)	41 (9.2)	119 (6.6)	6 (4.1)	48 (5.6)	54 (5.4)	84 (5.6)	89 (6.9)	173 (6.2)
Sometimes (%)	134 (9.8)	56 (12.6)	190 (10.5)	4 (2.8)	57 (6.7)	61 (6.1)	138 (9.2)	113 (8.7)	251 (9.0)
Yes (%)	1,149 (84.4)	347 (78.2)	1,496 (82.9)	135 (93.1)	747 (87.7)	882 (88.5)	1,284 (85.3)	1,094 (84.4)	2,378 (84.9)
Total	1,361 (75.4)	444 (24.6)	1,805 (100.0)	145 (14.5)	852 (85.5)	997 (100.0)	1,506 (53.7)	1,296 (46.3)	2,802 (100.0)
??	10.255**			4.055			2.088		

** $p < .01$ (two-tailed)

Social and Family Relationships

Table 37 summarizes results of interviews with HCBS and ICF/MR recipients regarding peoples' social and family relationships. The responses included only people determined to be able to respond independently and reliably.

Table 37. Social and Family Relationships of HCBS and ICF/MR Recipients with ID/DD in Six States

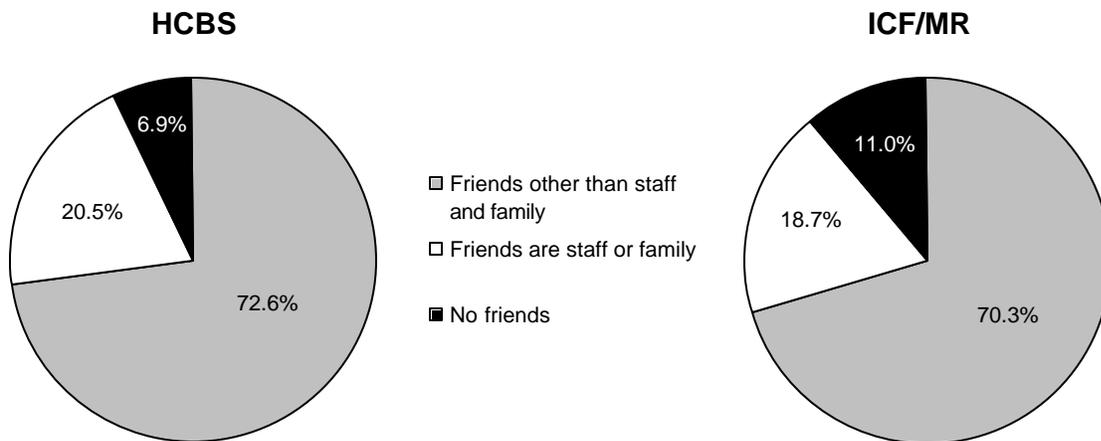
Question and Response	HCBS		ICF/MR		Total		Sig.
	N	%	N	%	N	%	
Have friends you like to talk to or do things with?							
Yes, friends other than staff or family	1,191	72.6	248	70.3	1,439	72.2	χ ² (2)=7.04 *
Yes, friends are staff or family	336	20.5	66	18.7	402	20.2	
No, does not have friends	114	6.9	39	11.0	153	7.7	
% of Total	1,641	82.3	353	17.7	1,994	100	
Have a best friend or someone you are really close to?							
Yes	1,334	87.0	268	83.0	1,602	86.3	χ ² =3.59
No	200	13.0	55	17.0	255	13.7	
% of Total	1,534	82.6	323	17.4	1,857	100	
See your friends when you want to see them?							
Yes	1,213	81.6	257	82.9	1,470	81.8	χ ² (2)=.34
Sometimes can't see them	198	13.3	39	12.6	237	13.2	
No, often unable to see friends	76	5.1	14	4.5	90	5.0	
% of Total	1,487	82.7	310	17.3	1,797	100	
Be alone with guests when they visit?							
Can be alone with guests	1,344	80.9	295	77.2	1,639	80.2	χ ² (2)=5.95*
Some restrictions or rules	175	10.5	39	10.2	214	10.5	
No, someone always must be present	142	8.5	48	12.6	190	9.3	
% of Total	1,661	81.3	382	18.7	2,043	100	
Can you see your family when you want to?							
Yes	1,157	76.4	240	74.1	1,397	76.0	χ ² =.79
Sometimes	254	16.8	59	18.2	313	17.0	
No	104	6.9	25	7.7	129	7.0	
% of Total	1,515	82.4	324	17.6	1,839	100	

* p < .05

Friendships. About 92% of HCBS and ICF/MR recipients reported having friends with whom they liked to talk or do things. For about 20% of respondents the “friends” were paid staff or family members and about 72% of these individuals were

people other than paid staff or family members (See Chart 18). People living in ICFs/MR were somewhat more likely ($p < .05$) to report having no friends than were HCBS recipients (11.0% and 6.9%, respectively), but for the most part the HCBS and ICF/MR recipients able to respond to this question provided very similar responses. For both groups it is striking that nearly 3 of 10 service respondents reported that they had no friends other than staff or family members.

Chart 18. Reported Friendships of HCBS and ICF/MR Recipients in Six States



Best friend/someone close. About 86% of HCBS and ICF/MR recipients (86.3%) also reported that they had someone on their lives that they considered a “best friend” or someone to whom they feel “really close” (either paid or unpaid). Only, about 82% of both HCBS and ICF/MR groups also reported being able to see their friends whenever they wanted to. Only, 5% of respondents indicated that they were often unable to see their friends.

Being alone with guests. About 80% of HCBS and ICF/MR respondents reported that they were not restricted in being alone with friends when they visited. Respondents reported a slightly higher rate of supervision of visits in ICFs/MR than among HCBS recipients’ homes (12.6% and 8.5%, respectively).

Family Involvement. About three-quarters of HCBS and ICF/MR recipients with available family members and excluding family members with whom a person lived reported being able to see members of their family whenever they wanted to. About 7.0% reported they could not see family members when they wanted to and 17.0% reported that sometimes they were limited in being able to see members of their families. Differences between HCBS and ICF/MR recipients were not statistically significant.

Employment and Other Day Programs

Table 38 summarizes the employment experiences of HCBS and ICF/MR recipients. Employment programs were reported under 5 broad categories: 1) supported

community employment; 2) group employment (enclave and crew work); 3) facility-based employment (sheltered workshop and work activity centers); 4) non-vocational day programs (day activity, day treatment, senior centers); and 5) other/none. Because many individuals with ID/DD participated in multiple vocational programs over the course of the work week, a total of 7 employment groupings are presented in Table 34 (and Table 39). These are: 1) supported employment (may include people with mix of supported employment and enclave/crew employment); 2) group (enclave/crew employment); 3) facility-based employment with supported and/or enclave/crew (group) components; 4) facility-based employment only; 5) non-vocational day programs with some facility-based or other work; 6) non-vocational day programs only and 7) other or no vocational day program.

Vocational Placements of HCBS and ICF/MR Recipients.

As shown in Table 38 nearly two-thirds (64.8%) of HCBS and ICF/MR recipients were reported to be in sheltered workshops or non-vocational day programs with or without work activity. Less than one-fifth (19.9%) were reported to participate in supported employment, group employment, or in sheltered employment settings that also provided community-based, supported or group employment component. About 15.3% of the sample members had no reported employment or day program, including 33 individuals 21 years and younger who were in school programs. HCBS recipients were substantially more likely than ICF/MR residents to be engaged in supported and group employment in community settings (18.0% and 2.6%). There were significantly different ($p < .001$) employment and day program experiences of HCBS and ICF/MR recipients. HCBS recipients had greater likelihood of being in non-center based community work for all or part of their day than was the case with ICF/MR recipients (23.0 % and 8.2%, respectively).

Table 38. Employment and Other Daytime Programs of HCBS and ICF/MR Recipients in Six States

Employment Type	HCBS		ICF/MR		Total	
	N	%	N	%	N	%
Supported Employment	313	14.1	14	2.4	327	11.7
Group Employment	86	3.9	1	0.2	87	3.1
Facility-Based with Supported or Group	110	5.0	32	5.6	142	5.1
Facility-Based Employment Only	499	22.5	147	25.6	646	23.2
Non-Vocational w/ Work Activity	205	9.3	161	8.0	366	13.1
Non-Vocational Only	647	29.2	148	25.7	795	28.5
Other/None	354	16.0	72	12.5	426	15.3
Total	2214	100.0	575	100.0	2789	100.0

$\chi^2 = 203.29$; * $p < .001$

Vocational Placement and Level of ID

A major factor in the differences in vocational/outcomes of HCBS and ICF/MR are the differences between HCBS and ICF/MR recipients in levels of intellectual disability. Table 39 shows that there is also the high degree of association between level of ID and the type of vocational programs. Whereas, persons with mild or no intellectual disability made up 41.4% of the total sample with level of ID and vocational data, they made up 70.0% of sample members in supported or group (enclave or crew) community employment. Persons with severe and profound intellectual disability made up 33.8% of the sample, but 55.8% of the persons in non-vocational day services with no work activities. Despite general social preferences for employment programs, as indicated in Table 39, there were no notable differences in the proportion of participants in the various employment/day programs expressing dislike for the program in which they were participating (a range from 2.7% to 5.5% expressing dislike).

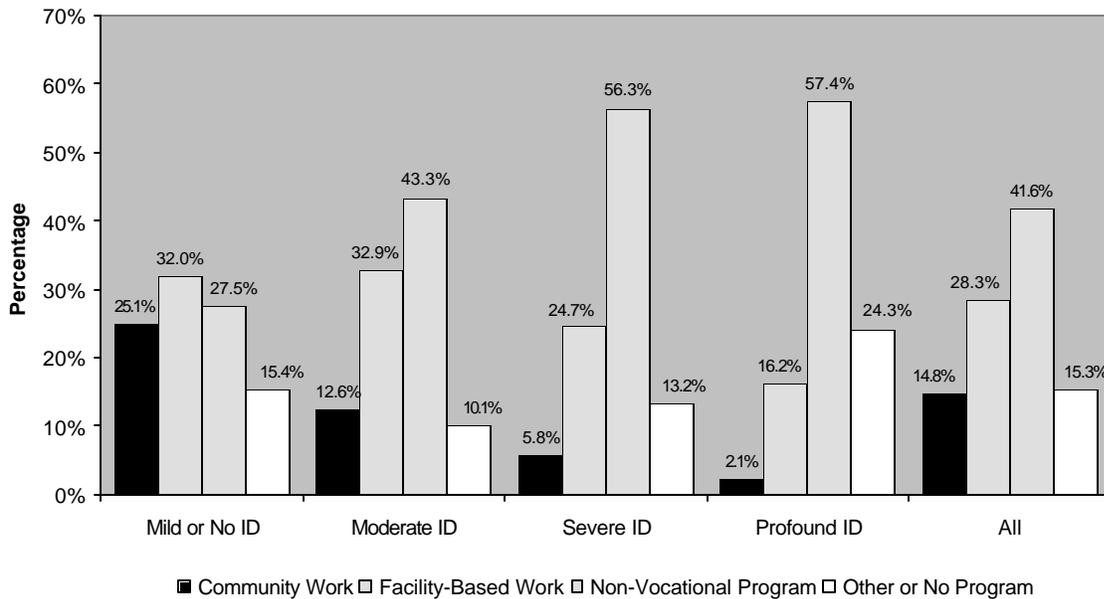
Table 39. Employment and Other Daytime Programs of HCBS and ICF/MR Recipients with Different Levels of ID in Six States

Employment Type	Level of Intellectual Disability								Total N	Total %	% Disliking
	Mild/No		Moderate		Severe		Profound				
	N	%	N	%	N	%	N	%	N	%	
Supported Employment	245	21.2	64	9.3	12	2.6	6	1.2	327	11.7	3.4
Group Employment	45	3.9	23	3.3	15	3.2	4	0.8	87	3.1	2.7
Facility-Based w/ Supported Group	84	7.3	48	7.0	10	2.2	0	0.0	142	5.1	5.0
Facility-Based Only	285	24.7	179	25.9	104	22.5	78	16.2	646	23.2	4.0
Non-Vocational w/ Work Activity	30	11.2	120	17.4	66	14.3	50	10.4	366	13.1	4.1
Non-Vocational Only	189	16.3	186	27.0	194	42.0	226	47.0	795	28.5	4.4
None/Other	178	15.4	70	10.1	61	13.2	117	24.3	426	15.3	5.5
Total	1156	100.0	690	100.0	462	100.0	481	100.0	2789	100.0	4.1

$\chi^2 (3) 522.55, p < .001$

Chart 19 shows the distribution of all HCBS and ICF/MR recipients by broad categories of vocational program and level of intellectual disability (ID). It combines supported and community enclave and crew employment into “community work,” it shows the substantial association between level of ID and vocational/day activities. For example while about a quarter (24.6%) of HCBS and ICF/MR recipients with mild or no ID were placed in non-vocational day programs, about 60% (59.8%) of sample members with profound ID were.

Chart 19. Distribution of HCBS and ICF/MR Recipients in Various Types of Employment and other Daytime Programs by Level of ID in Six States



Satisfaction and Choice with Work or Other Day Programs

Table 40 presents differences in responses of HCBS and ICF/MR recipients able to respond to questions about their primary work or other daytime program or activity.

Table 40. Satisfaction of HCBS and ICF/MR Recipients with Place and Staff of Work and Other Day Programs in Six States

Question and Response	HCBS		ICF/MR		Total		Sig.
	N	%	N	%	N	%	
Do you like the place or job you go to during the day							
Yes	1,390	90.8	290	89.0	1,680	90.5	χ ² =1.427
In-between	82	5.4	19	5.8	101	5.4	
No	59	3.9	17	5.2	76	4.1	
% of Total	1,531	82.4	326	17.6	1,857	100	
Are the staff at job or activity nice to you							
Yes, most are nice	1,357	93.6	281	88.9	1,638	92.8	χ ² (z)=13.362 ***

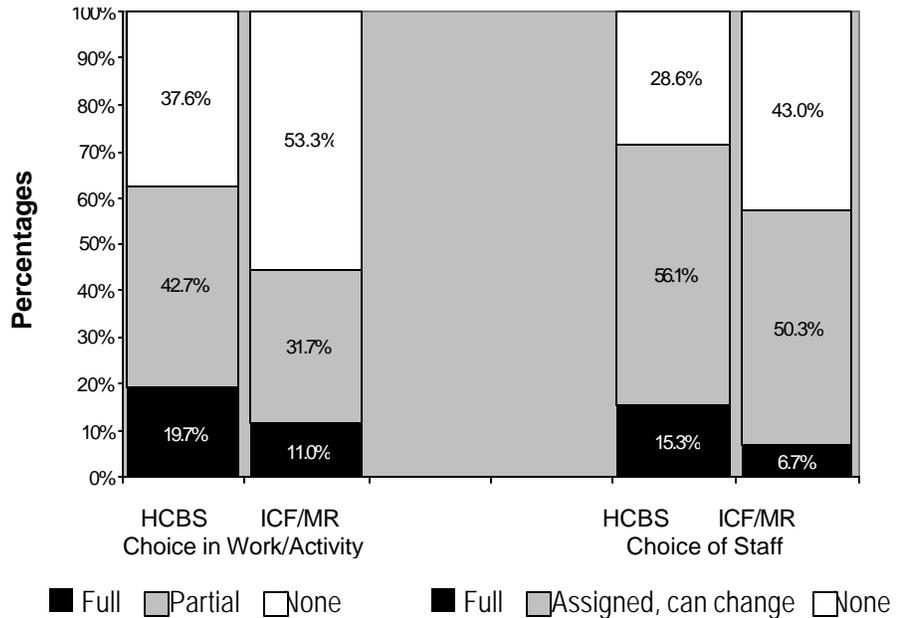
Some staff are nice	78	5.4	24	7.6	102	5.8
No, most staff are not nice	15	1.0	11	3.5	26	1.5
% of Total	1,450	82.1	316	17.9	1,766	100

*** p < .001

Both HCBS and ICF/MR recipients (only those able to respond) reported high levels of satisfaction with their work or day programs, with 90.5% of the responding sample members reporting that they liked the place they went for work or other day activities (90.8% of HCBS and 89.0% of ICF/MR recipients, respectively). Only 4.1% of sample members (3.9% of HCBS recipients and 5.2% of ICF/MR recipients) said they did not like their primary place of work or day activity. The differences between HCBS and ICF/MR respondents were not statistically different. There were, however, small differences between perceptions of support staff in the work or other day settings of HCBS and ICF/MR recipients. While high proportions of all responding sample members reported that most of the staff were “nice and polite” to them (92.8%), the proportions of HCBS recipients reporting in the affirmative (93.6%) was statistically greater than the ICF/MR respondents (88.9%). The proportion say that “most staff are not nice and polite” to them was similarly lower among HCBS respondents (1.0%) than among ICF/MR respondents (3.5%), but very low overall.

HCBS recipients were considerably more likely to report independent or shared choice decisions about their work or other day activity setting and the people who support them in those settings (62.4% and 42.7%). HCBS recipients were also considerably more likely than ICF/MR residents to report having chosen the people who support them or to have authority to request a change if not satisfied (68.5% and 51.0%, respectively). Chart 20 shows these statistically significant differences.

Chart 20. Proportions of HCBS and ICF/MR Respondents Reporting Choice in the Place and Staff of Primary Work or Other Daytime Activity



Routine Health and Dental Care

Table 41 presents reported frequencies of routine preventative health care for HCBS and ICF/MR recipients. In general it suggests that recommended preventative practices are not always adhered to.

Table 41. Frequency of Medical and Dental Exams of HCBS and ICF/MR Adult Recipients in Six States

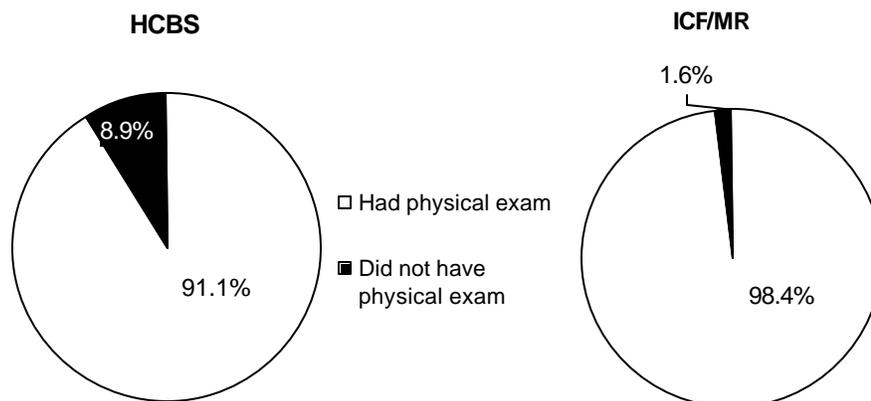
Last Saw Health Professional For:	HCBS		ICF/MR		Total		Sig.
	N	%	N	%	N	%	
Physical Exam							
Within last year	2,075	91.1%	555	98.4%	2,630	92.5%	X ² =35.048 ***
Over a year ago	203	8.9%	9	1.6%	212	7.5%	
% of Total	2,278	80.2%	564	19.8%	2,842	100.0%	
OB/GYN Exam (Women Only)							
Within last year	548	71.9%	176	85.4%	724	74.8%	X ² =17.569 ***
Over a year ago	146	19.2%	25	12.1%	171	17.7%	
Never	68	8.9%	5	2.4%	73	7.5%	
% of Total	762	78.7%	206	21.3%	968	100.0%	
Dental Exam							
Within last 6 month	1,345	64.1%	385	70.4%	1,730	65.4%	X ² =7.623 **
Over 6 months ago	754	35.9%	162	29.6%	916	34.6%	
% of Total	2,099	79.3%	547	20.7%	2,646	100.0%	

** p < .01 *** p < .001

Physical Exams

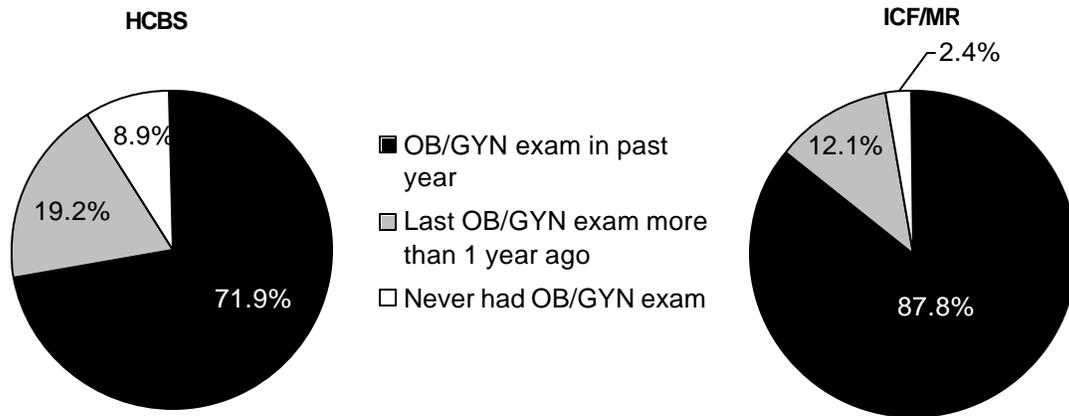
In the area of general physical exams 92.5% of sample members were reported to have had a physical examination the previous year with HCBS recipients being less likely (p<.001) to have had a physical than ICF/MR residents (90.7% and 98.5%). This is shown in Chart 21.

Chart 21. Proportions of HCBS and ICF/MR Recipients Reported to Have a Physical Exam in the Past 12 Months



As shown in Chart 22 women residing in ICFs/MR were considerably more likely ($p < .001$) to have had an OB/GYN exam in the previous year than HCBS recipients (85.4% and 71.9%). They were also less likely to be reported to have never had an OB/GYN exam (2.4% and 8.9%).

Chart 22. Proportions of Adult Women Receiving HCBS and ICF/MR Financed Services who had OB/GYN Exams in the Past 12 Months in Six States



Dental Exams

As shown in Table 41 and in Chart 23 reported access to routine dental exams fell far below the recommended standard of at least semi-annually. Only 65.4% of sample members were reported to have had a dental exam in the previous 6 months. A higher proportion ($p < .01$) of ICF/MR residents were reported to have seen a dentist in the past 6 months than HCBS recipients (70.4% and 64.1%, respectively).

Chart 23. Proportions of Adult HCBS and ICF/MR Recipients Who Had Dental Examination in Past Six Months in Six States



Service Access and Experiences by Race/Ethnicity

This section examines variations in service use by racial and ethnic differences among HCBS and ICF/MR recipients. Racial/ethnic distinctions made were: a) white, b) black, and c) hispanic and other. Such broad categories were necessitated by small sample sizes in more defined groupings (see Table 5 for the sample breakdowns)..

Access to HCBS and ICF/MR by Racial/Ethnic Groups

Table 42 provides a summary of relative enrollments in HCBS as compared to ICF/MR for persons with ID/DD from three racial/ethnic groupings (white non-Hispanic, black non-Hispanic and, as a group, persons identified as Hispanic, Native American, Asian and from other racial/ethnic backgrounds). Further breakdowns are provided into categories of mild/moderate and severe/profound ID. Among persons with mild or moderate ID, white non-Hispanics and black non-Hispanics had slightly, but statistically significant ($p < .05$), higher placement rates into ICFs/MR than did individuals from the other racial/ethnic groups as a whole. For sample members with severe/profound ID and for the sample as a whole there were no differences in the relative rates of HCBS and ICF/MR service use by racial/ethnic grouping.

Table 42. Differential Use of HCBS and ICF/MR Programs for Persons of Different Races by Level of Intellectual Disability in Six States

Racial / Ethnic Groups	Level of Intellectual Disability								
	Mild/Moderate			Severe/Profound					
	HCBS	ICF/MR	Total	HCBS	ICF/MR	Total	HCBS	ICF/MR	Total
White (%)	1,269 (87.9)	206 (89.6)	1,475 (88.2)	472 (87.6)	257 (86.2)	729 (87.1)	1,741 (87.8)	463 (87.7)	2,204 (87.8)
African American (%)	78 (5.4)	18 (7.8)	96 (5.7)	39 (7.2)	24 (8.1)	63 (7.5)	117 (5.9)	42 (8.0)	159 (6.3)
Hispanic/Asian/Other/Mix (%)	96 (6.7)	6 (2.6)	102 (6.1)	28 (5.2)	17 (5.7)	45 (5.4)	124 (6.3)	23 (4.4)	147 (5.9)
Total (Column)	1,443 (86.3)	230 (13.7)	1,673 (100.0)	539 (64.4)	298 (35.6)	837 (100.0)	1,982 (79.0)	528 (21.0)	2,510 (100.0)
χ^2 (df=2)	7.407*			.302			5.342		

Note: Percentages are in parentheses. * $p < .05$ (two-tailed)

Size of Living Arrangement by Racial Grouping

Table 43 summarizes the average number of individuals with disabilities with whom sample members lived by level of intellectual disability (ID) and by racial/ethnic grouping. It shows the substantial relationship between level of ID and the number of persons with whom the sample members lived (ranging from an average of 3.25 for persons with mild (or no) ID, to 4.1 for persons with moderate ID, to 6.7 for persons with severe ID, to 14.6 for sample members with profound ID. Although the differences between level of ID and number of persons sharing a home was notable and statistically significant ($p < .001$), no differences were found in the number of persons sharing a residence by racial/ethnic group. There were no differences in the proportion of sample members in the different racial/ethnic groups by level of ID.

Table 43. Number of Residents in Homes of Persons with ID/DD Receiving HCBS and ICF/MR Services in Six States by Level of Intellectual Disability and Race

Racial / Ethnic Groups	Level of Intellectual Disability				Total
	Mild	Moderate	Severe	Profound	
White					
Mean	3.29	4.24	6.56	14.41	5.95
Standard Dev.	5.98	8.36	13.49	33.38	16.38
African American					
Mean	2.02	3.53	8.00	24.27	7.44
Standard Dev.	1.87	3.23	16.70	28.15	15.96
Hispanic and Other					
Mean	3.14	3.58	4.00	6.80	3.76
Standard Dev.	1.96	2.68	1.00	6.02	2.97
Total					
Mean	3.25	4.08	6.72	14.64	5.96
Standard Dev.	5.96	7.86	13.73	32.73	16.02
Effects: Level of ID ($F[3,2489]=15.728$) ^{***} ; Race ($F[4,2489]=1.171$); Level of ID x Race ($F[12,2489]=1.434$)					
Significance Tests: <i>Level of ID:</i> Mild < Severe ^{**} ; Mild < Profound ^{***} ; Moderate < Severe [*] ; Moderate < Profound ^{**} ; Severe < Profound ^{**} ; <i>Race:</i> No significant differences were found among racial groups					
<i>Note:</i> The sample size is 1063 for those with mild disability, 595 for those with moderate disability, 405 for those with severe disability, and 426 for those with profound disability, while 2,192 for white, 156 for African Americans, 42 for Hispanic, 53 for Native American, and 46 for Asian/Pacific/Other/Mixed. Significance test is based on Bonferroni method. * $p < .05$; ** $p < .01$; *** $p < .001$ (two-tailed)					

Support-Related Choice by Race/Ethnicity

Table 44 summarizes the scores on the Support Related Choice subscale by level of ID and racial/ethnic group. As noted earlier level of ID is highly associated with scores on the Support Related Choice subscale, with each successively higher level of ID

being associated with greater participation in major support related decisions ($p < .001$). Controlling for level of ID, race/ethnic group had no association with the degree of individual control over major support-related decisions; nor was any interaction effect detected between level of ID and race on the support-related choice score.

Table 44. Support Related Choice by Residents with ID/DD Receiving HCBS and ICF/MR Services in Six States by Intellectual Level and Race

Racial / Ethnic Groups	Level of Intellectual Disability				Total Mean
	Mild Mean	Moderate Mean	Severe Mean	Profound Mean	
White	.97	.85	.62	.36	.76
African American	1.01	.84	.68	.37	.78
Hispanic/Asian/Other/Mixed	1.00	.85	.58	.34	.79
Total	.98	.84	.62	.36	.77

Effects: Level of ID ($F[3,2256]=54.199$)^{***}; Race ($F[2,2256]=1.602$); Level of ID x Race ($F[6,2256]=.569$)

Significance Tests: *Level of ID:* Mild > Moderate^{***}; Mild > Severe^{***}; Mild > Profound^{***}; Moderate > Severe^{**}; Moderate > Profound^{**}; Severe > Profound^{**};

Note: The sample size is 971 for those with mild disability, 534 for those with moderate disability, 365 for those with severe disability, and 386 for those with profound disability, while 1,991 for white, 142 for African Americans, and 123 for Hispanic/Asian/Other /Mixed. Significance test is based on Bonferroni method.

^{*} $p < .05$; ^{**} $p < .01$; ^{***} $p < .001$ (two-tailed)

Personal Choice by Race/Ethnicity

Table 45 summarizes the scores on the Personal Daily Choice subscale by level of ID and racial/ethnic group. The level of ID was highly associated with scores on the Personal Daily Choice subscale index, with higher levels of ID being associated with greater personal choice in daily life in all comparisons ($p < .001$). Controlling for level of ID, race/ethnic group had no association with the degree of individual control over personal choice in everyday life; nor was any interaction effect detected between level of ID and race on the personal choice scale score.

Table 45. Personal Choice of Recipients of HCBS and ICF/MR Services in Six States by Level of Intellectual Disability and Race

Racial / Ethnic Groups	Level of Intellectual Disability				Total Mean
	Mild Mean	Moderate Mean	Severe Mean	Profound Mean	
White	1.58	1.39	1.13	.77	1.32
African American	1.69	1.49	1.15	.67	1.34
Hispanic and Other	1.55	1.41	1.15	.69	1.31
Total	1.59	1.40	1.14	.76	1.32

Effects: Level of ID (F[3,2472]=106.136^{***}); Race (F[2,2472]=.421); Level of ID x Race (F[6,2472]=.802)

Significance Test: *Level of ID:* Mild > Moderate^{***}; Mild > Severe^{***}; Mild > Profound^{***}; Moderate > Severe^{***}; Moderate > Profound^{***}; Severe > Profound^{***}; *Race:* No significant differences were found among racial groups

Note: The sample size is 1,056 for those with mild disability, 590 for those with moderate disability, 400 for those with severe disability, and 426 for those with profound disability, while 2,172 for white, 157 for African Americans, and 143 for Hispanic/Asian/Other /Mixed. Significance test is based on Bonferroni method.
^{***}p <.001, ^{**}p<.01, ^{*}p <.05 (two-tailed)

Community Inclusion by Race/Ethnicity

Table 46 presents scores on the Community Inclusion Scale by level of ID and racial/ethnic group. The level of ID was general associated with scores on the Community Inclusion subscale, with higher levels of ID being associated with modestly greater participation in daily life decisions in all comparisons except between persons with mild and moderate ID, which were equal. Controlling for level of ID, race/ethnic group had no association with the degree of community inclusion; nor was any interaction effect detected between level of ID and race on the community inclusion subscale score.

Table 46. Community Inclusion of Persons with ID/DD Receiving HCBS and ICF/MR Services in Six States by Level of Intellectual Disability and Race

Racial / Ethnic Groups	Level of Intellectual Disability				Total Mean
	Mild Mean	Moderate Mean	Severe Mean	Profound Mean	
White	1.53	1.53	1.46	1.35	1.49
African American	1.53	1.50	1.51	1.44	1.50
Hispanic/Asian/Other/Mixed	1.46	1.50	1.44	1.45	1.47
Total	1.52	1.52	1.47	1.36	1.49

Effects: Level of ID (F[3,250])=3.571)*; Race (F[3,2503]=.541); Level of ID x Race (F[6,2503]=1.009)

Significance Test: *Level of ID:* Mild > Severe*; Mild > Profound***; Moderate > Severe*; Moderate > Profound***; Severe > Profound***; *Race:* No significant differences were found among racial groups

Note: The sample size is 1,066 for those with mild disability, 601 for those with moderate disability, 407 for those with severe disability, and 429 for those with profound disability, while 2,197 for white, 159 for African Americans, and 147 for Hispanic/Asian/Other /Mixed. Significance test is based on Bonferroni method.

* p <.05 (two-tailed); ** p<.01, *** p <.001

Expenditures for HCBS and ICF/MR

This section of the report summarizes expenditures for the Medicaid HCBS and ICF/MR in four states (see Methods section for details). In addition to the long-term service and support expenditures, Medicaid state plan services were also included in the expenditure records for each individual sample member. Table 47 and Chart 24 show HCBS recipients have on average substantially greater state plan expenditures than ICF/MR recipients (an average of \$7,363 and \$2,097, respectively). This difference reflects the more comprehensive (institutional) programs of ICF/MR settings which tend to bundle more services, including health services under a single payment than do providers of HCBS.

Components of Expenditures

Medicaid expenditures for HCBS and ICF/MR recipients were broken down into Medicaid State Plan and HCBS or ICF/MR components. The state plan services

were broken down into 6 categories (prescribed drugs, medical, social services, personal care, home health and non-HCBS therapies). Expenditures in these categories were summed for HCBS, ICF/MR and all sample members.

Table 47. Average Annualized Medicaid Expenditures for Adults (18 and Older) Receiving HCBS or ICF/MR Services in Four States

OTHER MEDICAID EXPENSES	HCBS N=1,231	ICF/MR Mean	Total Mean
Prescribed Drugs	\$3,294	\$1,704	\$3,066
Medical Expenses	\$1,725	\$368	\$1,545
Social Service Expenses	\$1,874	\$25	\$1,629
Personal Care	\$0	\$0	\$0
Home Health Care	\$220	\$0	\$191
Non-Waiver Therapies	\$250	\$1	\$217
TOTAL OTHER MEDICAID EXPENSES	\$7,363	\$2,097	6,648
HCBS / ICF-MR EXPENSES	Mean	Mean	
ICF / MR	N/A	\$126,178	
Residential Expenses	\$26,997	N/A	
Personal Assistance Expenses	\$11,971	N/A	
Respite Care	\$562	N/A	
Day Service Expenses	\$9,961	N/A	
Nursing Expenses	\$1,659	N/A	
Therapy Expenses	\$1,158	N/A	
Environmental Modifications	\$67	N/A	
Supplies & Equipment	\$103	N/A	
Transportation Expenses	\$0	N/A	
Training Expenses	\$107	N/A	
Case Management Expenses	\$1,561	N/A	
Other Expenses	\$261	N/A	
TOTAL HCBS/ICF-MR	\$54,407	\$126,588	
GRAND TOTAL	\$61,770	\$128,275	

Chart 24. Average Annual Medicaid Expenditures for Adults Receiving HCBS and ICF/MR Services in Four States

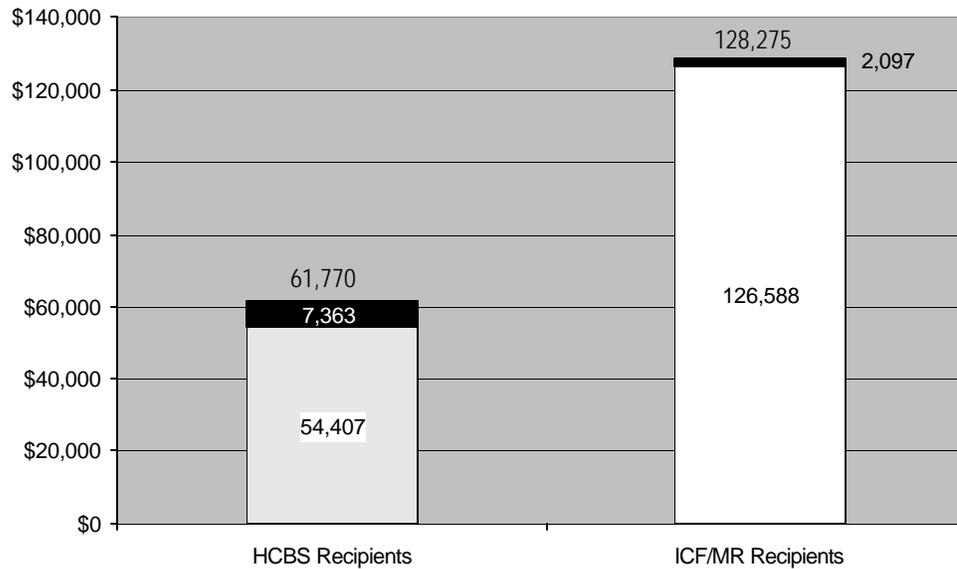


Table 47 also provides the annualized expenditure average for all HCBS recipients according to HCBS service categories (for ICF/MR residents ICF/MR is the lone service category). Residential supports had by far the largest average expenditure for HCBS recipients (an average of \$26,997 per person), followed by personal assistance services (an average of \$11,971 per person) and day/vocational services (an average of \$9,961). An average of less than \$110 per person per year was spent on transportation, environmental modifications, supplies and equipment, and training. It is important to recognize these average per person annualized HCBS expenditures reflect state service codes assigned to a common set of categories by state officials to create a uniform description of HCBS services. Distinctions between certain categories such as residential and personal assistance services are not always easily made. As such, it seems notable that 71.6% of HCBS expenditures went to services categorized as residential or personal care, as did 63.1% of all Medicaid expenditures for HCBS recipients.

Diagnostic Health, Physical and Sensory Indicators

Table 48 presents a summary of annualized Medicaid expenditures for HCBS and ICF/MR recipients by a) level of intellectual disability, b) reported frequency of needed health care from a nurse or physician, c) mobility limitations and d) visual limitations. It shows not only the consistency lower in Medicaid expenditures for persons receiving HCBS, but also a much more consistent association between intellectual, health, physical and sensory impairment and Medicaid expenditures for services to HCBS recipients than to ICF/MR. For example, Medicaid billings on behalf of HCBS recipients by level of ID increase progressively as level of ID becomes more severe. While a tendency to do so is also evident for ICF/MR recipients, it is much less regular than for HCBS recipients. In other of the characteristics shown (frequency of

medical care needed, mobility and vision), HCBS recipients had Medicaid expenditures that were much more directly related to indicators of impairment than did ICF/MR recipients. In only one area did Medicaid expenditures for HCBS recipients exceed those for ICF/MR recipients: for persons requiring the medical care of a nurse or physician on a daily or more frequent basis. Such a finding may reflect some economies in delivering such services in ICF/MR settings, but may also reflect the leveling effect on facility-based billings for institutional services. It seems likely that the actual health service costs for persons who need daily health care may be underestimated in ICF/MR billings, just as they may be overestimated for persons with relatively few health care needs. Because ICF/MR rates are usually set for a facility nor for individual residents, as in other “managed care” models, the average per person program level cost may overestimate the costs of these with high health care needs and underestimate the costs of those with relatively low health care needs.

Table 48. Annual Medicaid Expenditures for Adult HCBS and ICF/MR Recipients by Selected Characteristics

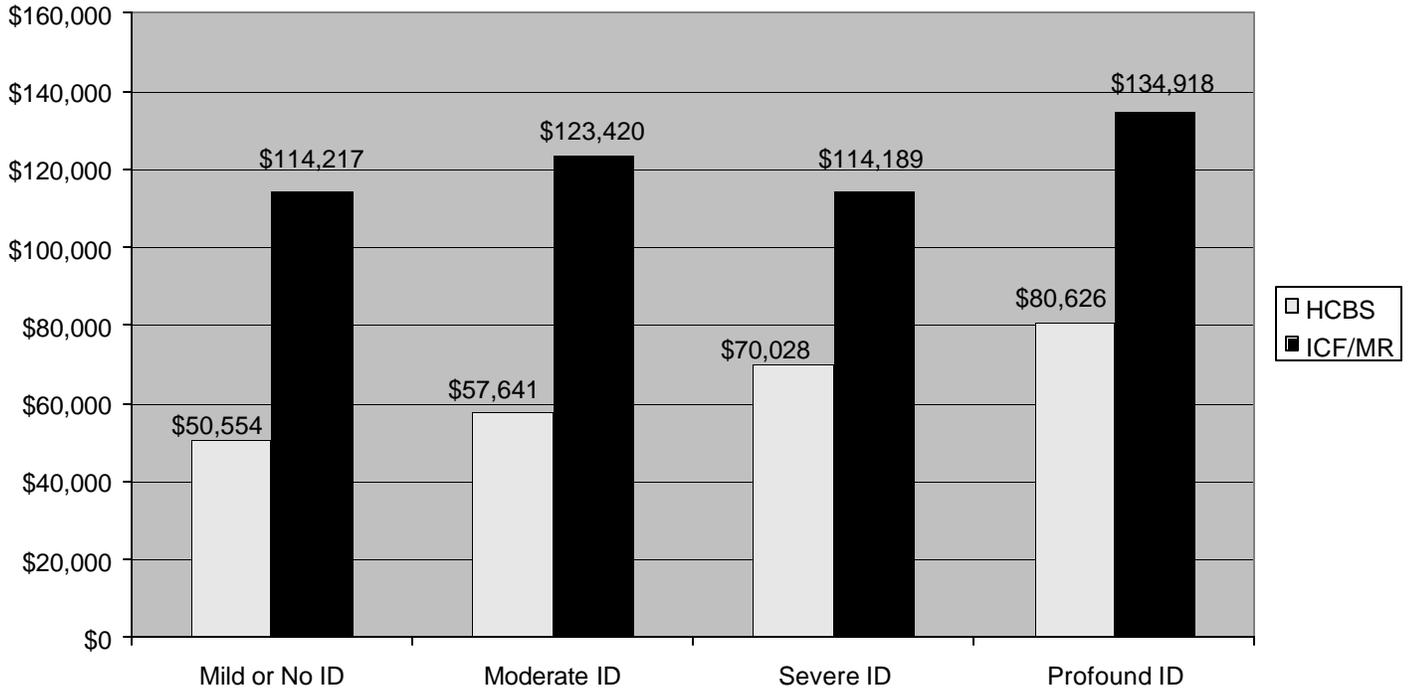
Characteristic	Medicaid Expenditures for Recipients of:		
	HCBS	ICF/MR	Total
Level of Intellectual Disability			
Mild or none	\$50,554 (N=473)	\$114,217 (N=18)	\$52,888 (N=491)
Moderate	\$57,641 (N=298)	\$123,420 (N=24)	\$62,540 (N=322)
Severe	\$70,028 (N=190)	\$114,189 (N=32)	\$76,174 (N=222)
Profound	\$80,626 (N=246)	\$134,918 (N=115)	\$97,921 (N=361)
Frequency of Medical Care Needed			
Less than once per month	\$56,186 (N=923)	\$130,188 (N=29)	\$58,440 (N=952)
At least monthly, but not weekly	\$60,605 (N=200)	\$119,798 (N=36)	\$76,414 (N=236)
At least weekly, but not daily	\$82,501 (N=66)	\$140,012 (N=19)	\$95,356 (N=85)
Daily or more	\$137,483 (N=33)	\$128,527 (N=106)	\$130,294 (N=139)
Mobility			
Ambulatory (with or without aids)	\$57,761 (N=1,083)	\$127,339 (N=125)	\$64,685 (N=1,208)
Non-ambulatory	\$91,305 (N=147)	\$133,921 (N=64)	\$104,232 (N=211)
Vision			
Sees well (with or without lenses)	\$60,087 (N=1,088)	\$127,339 (N=148)	\$68,099 (N=1,236)
Visual problems limit activities	\$68,107 (N=88)	\$133,296 (N=25)	\$82,531 (N=113)
Legally blind or substantially limited	\$86,264 (N=51)	\$130,946 (N=16)	\$96,934 (N=67)
ALL	\$61,770 (N=1,230)	\$128,275 (N=190)	\$70,601 (N=1,420)

Statistical significances: Level of ID was associated with expenditures in HCBS ($F[3,1392]=38.21$, $p<.001$), in ICF/MR ($F[3,185]=6.57$, $p<.001$) and for all recipients ($F[3,1392]=90.03$, $p<.001$). HCBS is associated with lower expenditures than ICF/MR for all levels of ID. **Frequency of medical care needed (from a nurse or physician)** was associated with expenditures in HCBS ($F[3, 1218]=60.73$, $p<.001$), not in ICF/MR, but for all recipients ($F[3,1408]=151.26$, $p<.001$). **Mobility** was associated with expenditures in HCBS ($F[1,1228]=97.96$, $p<.001$), in ICF/MR ($F[1,187]=3.88$, $p<.05$) and for all recipients ($F[1,1417]=154.63$, $p<.001$). **Visual limitations** are associated with expenditures in HCBS ($F[2,1224]=11.80$, $p<.001$), not in ICF/MR but for all recipients ($F[2,1413]=17.80$, $p<.001$).

Chart 25 provides a graphic comparison of annual Medicaid long-term services

and “other Medicaid” expenditures for HCBS and ICF/MR costs for recipients by level of intellectual disability.

Chart 25. Average Annual Expenditures for Adults Receiving HCBS and ICF/MR Services by Level of Intellectual Disability in Four States



Behavioral Health Factors

Table 49 presents differences in Medicaid billings for HCBS and ICF/MR by a number of behavioral characteristics. These include: self-injurious and disruptive behavior, a mental health or psychiatric diagnosis and autism. The absence of self-injurious behavior was associated with lower expenditures among HCBS recipients ($p < .001$). There was a modest, but inconsistent association between self-injurious behavior and expenditures among ICF/MR recipients. For both HCBS and ICF/MR recipients there was a paradoxical tendency for people with higher frequencies of reported disruptive behavior to have lower average expenditures, although the association was statistically significant only among ICF/MR residents. The presence of a mental health/psychiatric diagnosis in addition to ID/DD (dual diagnosis) had no association with HCBS expenditures and a modest, inverse association with ICF/MR expenditures (i.e., expenditures were lower for persons with mental health/psychiatric diagnoses). A diagnosis of autism among HCBS recipients was associated with higher expenditures than for individuals without autism (\$76,868 and \$62,351 respectively, $p < .001$), but no difference was noted among ICF/MR residents.

Table 49. Annualized Medicaid Expenditures for Adults with HCBS and ICF/MR

Recipients by Selected Behavioral Health Indicators

Behavioral Indicators	Annualized Medicaid Expenditures for Recipients of:		
	HCBS	ICF/MR	Total
Self-Injurious Behavior			
None	\$58,440 (N=967)	\$130,0175 (N=115)	\$66,007 (N=1,082)
Less than 1 per month	\$74,518 (N=139)	\$120,933 (N=36)	\$84,066 (N=175)
1-3 per month	\$79,992 (N=83)	\$138,474 (N=25)	\$93,529 (N=108)
Weekly or more often	\$71,294 (N=23)	\$111,540 (N=10)	\$84,314 (N=33)
Disruptive Behavior			
None	\$60,263 (N=733)	\$137,673 (N=84)	\$68,222 (N=817)
Less than 1 per month	\$67,039 (N=94)	\$134,115 (N=9)	\$72,900 (N=103)
1-3 per month	\$64,079 (N=131)	\$113,273 (N=36)	\$74,676 (N=167)
Weekly or more often	\$64,341 (N=246)	\$122,364 (N=55)	\$74,782 (N=301)
Mental Health/Psychiatric Diagnosis			
No psychiatric diagnosis	\$61,928 (N=758)	\$132,330 (N=126)	\$71,963 (N=844)
Psychiatric diagnosis	\$64,896 (N=382)	\$120,875 (N=59)	\$72,385 (N=441)
Autism Diagnosis			
No Autism	\$65,351 (N=1,063)	\$128,112 (N=177)	\$71,699 (N=1,240)
Autism Diagnosis	\$76,868 (N=52)	\$131,233 (N=7)	\$83,325 (N=59)
<p>Statistical significances: Self-injurious behavior was associated with expenditures in HCBS (F[3,1208]=13.42, p<.001) and in ICF/MR (F[3,183]=3.15, p<.05), and among all recipients (F[3,1395]=20.19, p<.001). Disruptive behavior was not associated with expenditures for HCBS; but was in ICF/MR (F[3,180]=7.51, p<.001), but paradoxically by expenditures were greater for persons who were least often disruptive. There was an association between frequency of disruptive behavior and expenditures among all recipients. Dual diagnoses were not associated with expenditures in HCBS, or among all recipients, but there was a modest association between lower cost and the presence of a dual diagnoses among ICF/MR residents (F[1,183]=6.53, p<.05). Autism diagnosis was associated with expenditures in HCBS (F[1,1113]=6.19, p<.05), but not in ICF/MR.</p>			

Type of Residence

There was a strong association between Medicaid expenditures and the residential circumstances of HCBS and ICF/MR recipients. Four residential arrangements were identified: 1) congregate/agency-operated housing, 2) host family (also called foster, shared living or companion living), 3) own home (owned or rented by an individual or an apartment program with part-time staffing), and 4) family home (living with parents or other relatives). Table 50 presents a breakdown of Medicaid expenditures by type of residential arrangement. All ICF/MR residents resided in congregate/agency operated settings. Table 50 and Chart 26 show that Medicaid expenditures are substantially lower for adults living with parents or other relatives (only 40.6% of the average for all HCBS recipients and 35.5% of all recipients). Adults living in host family situations also had expenditures substantially below average for HCBS recipients (71.4% of the average HCBS expenditures and 62.4% of average

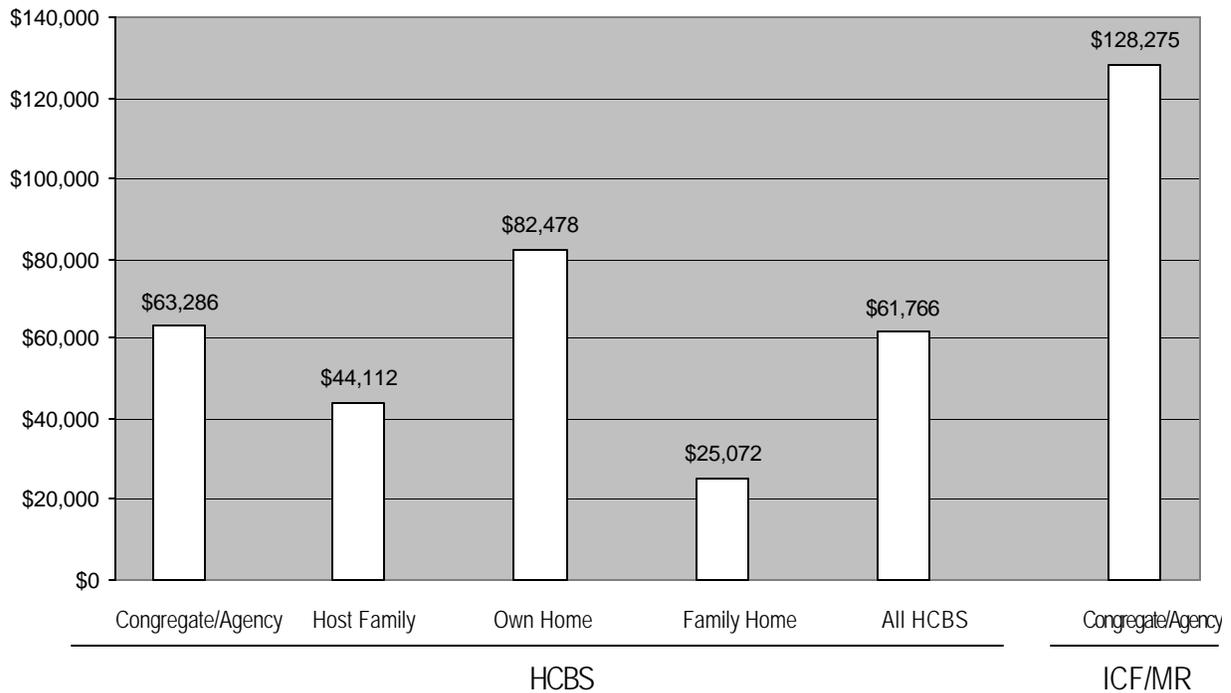
expenditures for all). The most costly arrangements on average were own home (133.5% of the average HCBS expenditures, but only 64.0% of the average ICF/MR expenditure). Congregate/agency-operated settings housed half (50.6%) of the HCBS recipients with slightly higher than average HCBS expenditures (102.5% of the average HCBS expenditure). Average expenditures for HCBS recipients in congregate/agency operated settings were still less than half (49.3%) of expenditures for ICF/MR residents of congregate/agency operated settings.

Table 50. Annualized Medicaid Expenditures for Adult HCBS and ICF/MR Recipients by Type of Residence

Home Type	Medicaid Expenditures for Recipients of:		
	<i>HCBS</i>	<i>ICF/MR</i>	<i>Total</i>
Congregate/Agency-Operated	\$63,286 (N=622)	\$128,275 (N=190)	\$78,344 (N=811)
Host Family	\$44,112 (N=80)	N/A	\$44,112 (N=80)
Own Home	\$82,478 (N=345)	N/A	\$82,671 (N=346)
Family Home	\$25,072 (N=182)	N/A	\$25,072 (N=182)
Total	\$61,766 (N=1,229)	\$128,275 (N=190)	\$70,600 (N=1,419)

Statistical significances: Home type was associated with expenditures in HCBS (F[3,1225]=110.28, p<.001) and among all recipients (F[3,1415]=107.63, p<.001). All ICFs/MR were classified as congregate/agency homes.

Chart 26. Annualized Medicaid Expenditures for Adult HCBS and ICF/MR Recipients by Type of Residence in Four States



Multi-Variate Analysis of Expenditures

HCBS expenditures were on average substantially less than ICF/MR expenditures, even including the greater payments for other Medicaid services for HCBS recipients. But has been noted throughout this report ICF/MR recipients tended to have on average more extensive support needs. For example, 20.4% of HCBS recipients were reported to have profound intellectual disability as compared with 60.8% of ICF/MR recipients; 39.2% of HCBS recipients were reported to have mild intellectual disability as compared with 9.5% of ICF/MR recipients. Similarly HCBS recipients in the sample when compared to ICF/MR recipients were less likely to need medical services of a nurse or physician on a monthly or more frequent basis (24.5% and 84.7%, respectively).

Table 51 is a correlation matrix that shows the high correlation between annualized expenditures and living in an ICF/MR (.50), higher medical care needs (.48), level of ID (.44) and living with parents/relatives (.37). There was a particularly high correlation between ICF/MR residence and reported medical care needs (.58), which may have reflected in part the presence of on-site medical personnel in the ICFs/MR in which some sample members lived. ICF/MR residence was also associated with level of ID (.35), but had weaker, but positive correlations with mobility (.23) and vision impairment (.11).

Table 51. Correlations Among Selected Variables and Annualized Expenditures for HCBS and ICF/MR Recipients with ID/DD in Four States (N=1,240*)

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
1. Annualized Expenditure	—																			
2. Level of ID	.440	—																		
3. Medical care needs	.477	.236	—																	
4. Mobility	.333	.263	.260	—																
5. Vision	.165	.174	.150	.204	—															
6. Self-injury	.188	.262	.124	.073	.115	—														
7. Disruptive behavior	.053	.000	.087	-.074	.068	.320	—													
8. MI/Psychiatric Dx	.008	-.221	.025	-.156	-.042	.063	.175	—												
9. Autism	.070	.111	.011	-.088	-.035	.120	.034	-.040	—											
10. Gender	-.012	-.005	.044	.009	.009	.031	.038	.082	-.054	—										
11. Age	-.001	-.035	.060	-.058	.050	-.042	-.033	.065	-.084	.033	—									
12. Type Home-Congregate	.186	.152	.248	.045	.076	.089	.099	.091	.023	-.026	.191	—								
13. Type Home-Host Family	-.155	-.001	-.087	-.041	-.029	-.019	-.036	-.019	.003	-.001	-.083	-.272	—							
14. Type Home-Own Home	.141	-.144	-.136	.003	-.059	-.049	-.048	-.016	-.009	.014	-.065	-.685	-.145	—						
15. Type Home-Family Home	-.372	-.037	-.133	-.045	-.017	-.057	-.061	-.106	-.026	.022	-.148	-.409	-.087	-.219	—					
16. ICF/MR person	.498	.355	.583	.235	.113	.163	.111	-.013	-.016	.013	.081	.359	-.098	-.246	-.147	—				
17. State 1	-.124	.169	-.059	-.129	-.043	.024	-.013	-.069	-.023	-.042	.066	.188	-.110	-.282	.178	.015	—			
18. State 2	-.012	.043	.191	.085	.039	.066	.053	.171	.032	-.012	.037	.110	.164	-.200	-.011	.134	-.228	—		
19. State 3	.308	.107	-.083	.074	-.003	.011	-.062	-.103	-.003	-.039	-.137	-.371	.038	.545	-.207	.072	-.337	-.311	—	
20. State 4	-.192	-.287	-.023	-.033	.008	-.086	.031	.023	-.003	.012	.050	.120	-.077	-.140	.063	-.094	-.336	-.310	-.458	—
<i>Mean</i>	72679.77	2.3	1.65		1.18	.37	1.06				1.72									
<i>SD</i>	45429.71	1.24	1.11		.495	.76	1.41				.81									
<i>%</i>				15				32	4	44		56.15	5.46	26.81	11.57	14.18	19.80	17.36	31.46	31.38

***Note:** The differences between 1,240 HCBS persons included on these correlations make up 87.3% the 1,421 persons in the total sample. Individual sample members were eliminated from the matrix if they had a missing value in any one of the variable included

Correlations such as shown in Table 51 demonstrated the need for multi-variate controls on co-linear variables in examining the aggregate contributions of such factors to overall expenditures. To examine the relationships between independent variables and annualized expenditures the ordinary least-squares (OLS) regression model was employed. Independent variables were ordered in blocks, including a) level of ID, b) health and sensory limitations, c) mental illness/psychiatric conditions, e) autism, f) gender, g) home/residential service type, h) HCBS or ICF/MR program participant and i) state. Table 52 presents the results of the OLS regression according to the blocks of variables identified above.

The results of the OLS regression showed that level of ID had a strong association with annualized expenditures, accounting for about 19 percent of a total variance ($R^2=.193$, $p<.001$). Within the second block of variables, medical care needs was a particularly strong predictor of annual expenditures. This entire block of independent variables increased the explained variance considerably (R^2 change = $.170$). Together the level of ID and health and sensory limitations accounted for more than one-third of the variance in annualized expenditures ($R^2=.36$) with all component factors except visual limitations contributing at statistically significant levels ($p < .001$). Challenging behavior as a block contributed little ($.003$) to the variance accounted by the equation. A dual diagnosis including psychiatric conditions contributed an additional $.008$ to the overall explained variance ($p<.001$); more so than a diagnosis of autism which had a small, but statistically significant effect on explained variance ($.001$; $p<.05$). Gender and age had no statistically significant association with variance in annualized expenditures (although in combination added $.002$ the R^2). Following the blocks of individual variables, the block of “home/residential service type” variables were added to the equation. Together they made a substantial contribution to explained variance (R^2 change= $.135$; $p<.001$ and total $R^2=.51$). After accounting for the variance accounted for by other individual and residential variables ICF/MR vs. HCBS participation also accounted for a statistically significant amount of variation in expenditures. Adding ICF/MR as a predictive variable accounted for statistically significant ($p<.001$) additional $.033$ in explained variation in expenditures, with the total $R^2=.55$. Finally, state as a series of dummy variables contributed to a statistically significant ($p<.001$) degree in accounted for variability in expenditures (R^2 change= $.021$). Controlling for all the other factors noted, states provided different amounts of funding for service to adults with ID/DD. Overall, the variables included in the regression analysis accounted for 57% of the variation in the annualized expenditures of the 1,240 individuals in the regression sample. Chart 33 shows the relative contributions of these blocks in accounting for variations in expenditures.

Table 52. Coefficients of a Regression of Selected Variables for HCBS and ICF/MR Recipients in Four States

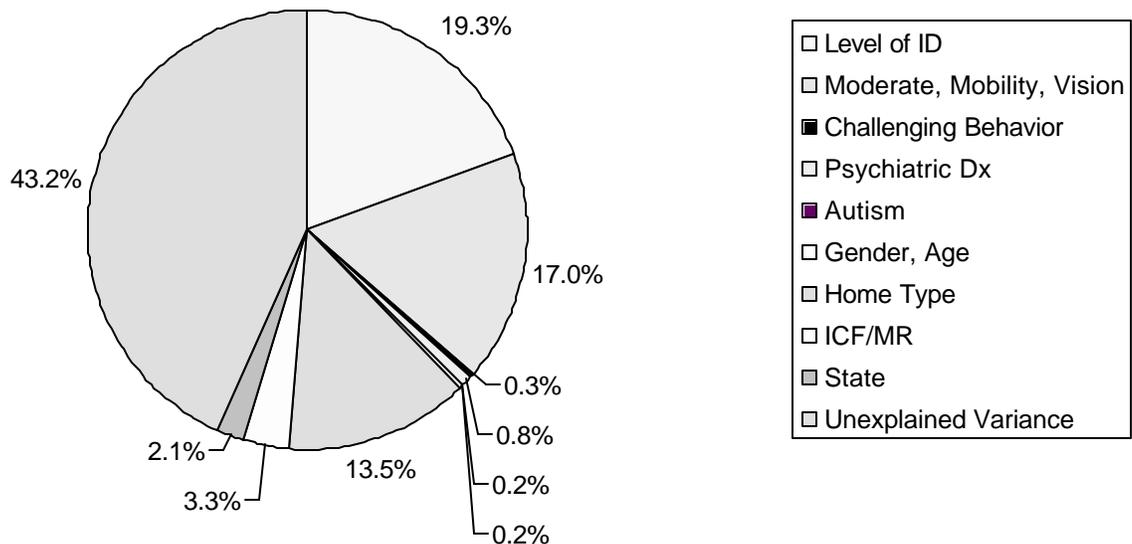
Independent	HCBS/ICF Annual Expenditure																	
	1		2		3		4		5		6		7		8		9	
	b	β	b	β	b	β	b	β	b	β	b	β	b	β	b	β	b	β
Level of MR	16071.035 (937.981)	.440***	11336.439 (884.614)	.310***	10932.811 (911.193)	.299***	11725.190 (928.118)	.321***	11534.131 (931.658)	.316***	11605.362 (933.255)	.318***	12433.893 (833.593)	.340***	10637.292 (827.025)	.291***	10189.144 (845.326)	.279***
Medical care			14727.127 (986.006)	.360***	14530.583 (990.254)	.355***	14191.038 (988.265)	.347***	14167.735 (987.058)	.347***	14290.604 (989.206)	.350***	13343.780 (894.746)	.326***	8658.290 (996.370)	.212***	10099.158 (1001.035)	.247***
Mobility ^a			19341.729 (3112.744)	.152***	19722.630 (3127.060)	.155***	21051.433 (3127.188)	.166***	21806.398 (3145.081)	.171***	21500.472 (3157.741)	.169***	17973.622 (2804.303)	.141***	16237.638 (2713.933)	.128***	16083.280 (2688.723)	.126***
Vision			2425.465 (2166.560)	.026	2010.264 (2172.044)	.022	2104.052 (2159.482)	.023	2296.377 (2158.766)	.025	2424.374 (2160.711)	.026	3151.695 (1914.804)	.034	3769.093 (1849.996)	.041	3376.979 (1811.834)	.037
Self-injury					2776.779 (1498.563)	.046	2336.144 (1494.034)	.039	2037.181 (1499.312)	.034	2007.435 (1500.256)	.034	1442.444 (1329.258)	.024	1100.210 (1283.977)	.018	1245.875 (1255.488)	.021
Disruptive behavior					565.558 (784.229)	.018	159.683 (786.482)	.005	159.685 (785.468)	.005	141.683 (785.793)	.004	-161.778 (697.595)	-.005	-576.005 (674.991)	-.018	-364.753 (661.125)	-.011
Mental illness/psychiatric diagnosis ^b							9124.831 (2326.289)	.094***	9326.296 (2325.397)	.096***	9756.645 (2335.710)	.100***	7357.408 (2082.077)	.076***	7370.756 (2010.350)	.076***	8733.577 (1997.264)	.090***
Autism ^b							10603.863 (5206.637)	.047 ⁺	9683.503 (5231.139)	.043	6776.081 (4636.910)	.030	6776.081 (4636.910)	.030	9477.129 (4486.304)	.042 ⁺	10077.865 (4397.787)	.045 ⁺
Gender ^c																		
Age																		
Type Home ^d																		
Congregate																		
Host Family																		
Own Home																		
Family Home																		
ICF/MR person ^e																		
STATE ^f																		
State 1																		
State 2																		
State 3																		
State 4																		
Intercept	35900.969 (2442.494)		16624.119 (3257.253)		16665.227 (3314.245)		12784.543 (3440.204)		12518.532 (3438.253)		15763.928 (4002.297)		22462.585 (3993.701)		27795.305 (3897.283)		20937.296 (4263.540)	
Adjusted R ²	.193		.361		.363		.370		.372		.373		.508		.541		.562	
R ²	.193		.363		.366		.374		.376		.378		.513		.546		.568	
R ² change	.193***		.170***		.003		.008***		.002 ⁺		.002		.135***		.033***		.021***	

***p<.001, **p<.01, *p<.05 (two-tailed test)

a. 0=ambulatory, 1= non-ambulatory; b. 0=no, 1=yes; c. 0=male, 1=female; d. Congregate is the reference group for type home variables; e. 0=HCBS, 1=ICF/MR; f. AL is the reference group for state dummy variables

***Note:** The differences between 1,240 HCBS persons included on these correlations make up 87.3% the 1,421 persons in the total sample. Individual sample members were eliminated from the matrix if they had a missing value in any one of the variable included. The numbers in parentheses are the standard errors of the b statistic which is the unstandardized coefficient. β is the standardized coefficient which reflects the relative importance of the variables in the regression equation.

Chart 27. Relative Amount of Variance in Expenditures for Adult HCBS and ICF/MR Recipients Accounted for by Selected Variables Multivariate Analyses of Expenditures



Limitations of the Study

There were numerous limitations to this study. Many of them related to the challenges of gathering reliable and valid data on the subjective experiences of persons with intellectual and developmental disabilities. In this study on some questions nearly 40% of the sample was unable to understand or respond to the question posed. These non-respondents represented individuals who presented the biggest challenges in achieving the national goals on which this evaluation was based, i.e., living integrated, self-determined lives. The missing data from individuals who were unable to reliably convey their perceptions of their services and lives were not substituted by proxy responses from family members or supports staff. Evidence suggests that the congruence between two such sources is not good-both may be valid from a perspective, but they are generally different. In the end then the sample became both smaller and somewhat skewed in trying to report the quality of supports and general quality of life of the individuals sampled. In the same vein comparisons between HCBS and ICF/MR services were affected by the differences in the samples. An effort was made both to report differences in outcomes of importance that are viewed as universally important, such as choice, respect, relationships, participation, but this was done knowing that such outcomes were associated with a number of individual variables, most notably degree of intellectual impairment. Efforts were made to balance such findings with multivariate analyses that control for individual characteristics. Other such limitations are also discussed in the methods section of the report.

While sampling within states is relatively straightforward, sampling of states is complex. States are all quite unique. The states selected provided in their aggregate on a number of measures indications of being similar to the nation as a whole, but they cannot be understood to represent a sample of all states. Such a sample is not possible to establish from any 6 states.

IV. SUMMARY

This report presents findings of a study of the characteristics, experiences and expenditures of a large sample of participants in the primary program providing long-term services and supports (LTSS) to persons with intellectual and developmental disabilities (ID/DD), Medicaid Home and Community Based Services (HCBS). It includes comparisons to a sample of participants in the Medicaid Intermediate Care Facility/Mental Retardation (ICF/MR) program. The ICF/MR was first authorized in 1971 as a new model of intermediate care. It provided the first ever Medicaid LTSS benefit specifically focused on persons with ID/DD. In 1981 the Medicaid Home and Community Based Services (HCBS) was authorized as an alternative to the institutional standards of Medicaid programs, including ICF/MR. As an “alternative” to ICFs/MR, HCBS was until the early 1990’s restricted in its expansion by the expectation that its growth would be generally equivalent to the ICF/MR expansion that could be avoided by providing HCBS. In the early 1990’s these restrictions were substantially loosened and in 1994 the link between the number of persons permitted to receive HCBS and the number of people who would otherwise be living in ICFs/MR was eliminated in revisions of HCBS regulations. As a result, after 1992 there was rapid growth in HCBS recipients with ID/DD, from about 62,500 in June 1992 to about 443,600 in June 2005. During the same period, there was steady decrease in populations of ICFs/MR, from 146,300 residents nationwide in June 1992 to 101,800 in June 2005 (Prouty, Smith & Lakin, 2006).

Parallel changes have been evident in Medicaid HCBS and ICF/MR expenditures. Between 1992 and FY 2005 annual federal and state expenditures for HCBS and ICF/MR services for people with ID/DD increased from \$10.5 billion to \$29.3 billion. HCBS expenditures, which increased from \$1.7 billion in 1992 to \$17.2 billion in 2005, made up 82.5% of this growth in total expenditures. Although total ICF/MR expenditures increased at a much slower rate than did HCBS expenditures between 1992 and 2005, from \$8.8 billion to \$12.1 billion (37%), they did so as the total number of ICF/MR recipients decreased by 30% (Prouty, Smith, & Lakin, 2005). Between 1993 and 2005, the average annual per-person expenditure for HCBS increased from \$25,176 to \$39,656 (57.5%), while the average annual per person expenditure for ICF/MR residents increased from \$62,180 to \$117,600 (89%). In terms of dollars adjusted by the Consumer Price Index the increases in average annual per person HCBS and ICF/MR expenditures were 18% and 47%, respectively (Prouty, Smith, & Lakin, 2006). Clearly Medicaid HCBS and ICF/MR expenditures, and especially the former, are playing a central, growing and diversifying role in providing LTSS to persons with ID/DD.

Comparisons of personal characteristics of adult (18 years and older) HCBS and ICF/MR recipients confirmed that the two groups differed along many dimensions,

including age, level of ID, psychiatric diagnosis, presence of seizures or neurological disorders, and care required from a nurse or physician. The ICF/MR sample was older, had more severe disability, a higher proportion with a psychiatric diagnosis and seizures/neurological disorder, and reportedly required more frequent medical care. Likewise, as expected, living arrangements differed between the two groups, with ICF/MR service users living in larger settings with more residents with ID/DD. There was overlap in some types of living settings used, but also important differences regarding living in congregate care settings (all ICF/MR residents and about half of HCBS recipients) and living in a parent's or relative's home, in a host family or shared living arrangement or in one's own home (HCBS users exclusively).

The differences between adult HCBS and ICF/MR recipients in personal characteristics and living arrangements need to be considered when examining the findings reported here. On the whole a person's level and type of disability is associated with different individual outcomes, irrespective of (controlling for) HCBS or ICF/MR program participation or even type of residential support. It is clear is that different disability characteristics carry different weights in terms of their effect on outcomes, and that certain characteristics are associated with generally similar patterns in experiences and outcomes. Overall, there was a consistent relation between level/type of disability and residence type, in that those with more severe intellectual disability or with an additional type of disability were more likely to live in agency-operated congregate settings. Level of intellectual disability had substantial association with HCBS or ICF/MR program participation, although these were greatly affected by state policy decisions about the way HCBS and ICF/MR options are used. Mobility and verbal communication skills were also very strongly associated with residential characteristics and appear to have significant influence opportunities self-determination. Visual impairments, and seizure disorder/neurological problems were related, but less strongly, to residential size and type, while the presence of challenging behavior appeared to be an important factor in where people lived. The presence of dual diagnosis was not strongly associated with all outcomes, and it appears to be quite distinct from the effect of the need for intensive behavioral supports. Perhaps the most striking result for people with dual diagnosis was the small percentage (9.4%) who reported living at home with a parent or relative. For most outcomes related to satisfaction and sense of well-being there was significantly and consistently less desirable outcomes among persons with dual psychiatric and intellectual disability diagnoses. It was important to note that HCBS financed programs generally supported as many or more people with all identified levels and types of disability than did ICFs/MR. This suggests that HCBS offers the flexibility to meet the needs for viable community alternative for all people who are currently institutionalized, including those with more severe and multiple disabilities.

Self-determination in this study has been defined by two scales: Personal Choice and Support Related Choice. Analysis of personal choice and support related choice outcomes indicated that individual characteristics, HCBS vs. ICF/MR program participation and size of residential setting were consistently associated with self-determination. Specifically, persons with relatively more severe levels of ID, placements in ICFs/MR and living in relatively larger settings, and persons living in congregate care

settings experienced lower levels of self-determination controlling for the other factors. Such controls were important to these analyses given that ICF/MR residents tended to have more severe levels of ID and to live in larger residential settings. The findings of these analyses supported the value of HCBS, especially as used to support people in relatively small, non-congregate living arrangements as a means of achieving increased self-determination, and demonstrated detriment to self-determination in efforts to increase the number of persons living together in pursuit of cost-containment. These analyses further support the strong tendencies among the states to reduce their use of ICFs/MR and to increase opportunities for persons with ID/DD to live in smaller community homes. At the same time it was notable that, although still statistically significant, how relatively small were the differences in self-determination outcomes between HCBS and ICF/MR financed services once individual characteristics, and type of housing (especially congregate/agency settings) were controlled. Clearly HCBS financing alone did not assure notably better outcomes for people with ID/DD.

There were few differences in satisfaction and sense of well-being between service users by HCBS and ICF/MR status, with no significant difference for most indicators. Significantly more HCBS users reported that work/day program staff members were nice and polite, whereas the opposite was the case regarding staff at home, with ICF/MR users reporting more favorably. HCBS users liked their home significantly more than ICF/MR users, but overall the vast majority of people reported liking their current living and work/day program arrangements and the staff who worked there. Loneliness was the most widespread problem, and there were also small percentages of people who reported negative outcomes in the other areas evaluated. Significant differences were evident for a few related outcomes but there was no consistent pattern favoring the HCBS or ICF/MR samples. The observed differences between samples were small, despite being statistically significant in several cases. These findings are consistent with previous research indicating that subjective indicators of quality of life have weak or no relations with objective features of service environments. The overall high level of well-being and satisfaction reported for most of indicators is generally consistent with the notion that average satisfaction will be about 75% of the scale maximum.

Examination of outcomes by home size was more consistent. Where significant differences were found, better outcomes were almost always associated with smaller residence size. Residents of larger settings significantly more often reported themselves to be lonely than those of smaller settings, with the main difference being due to loneliness in settings with 7 or more residents with ID/DD, where the majority reported feeling lonely sometimes or often. Likewise, service users from smaller settings liked their home significantly more. Given the fact that subjective measures of satisfaction and well-being rarely relate to objective features of the environment, the consistent findings favoring smaller living settings were notable, and provided further evidence to support the initiatives among the states to increase opportunities for persons with ID/DD to live in smaller homes in the community.

Comparisons among HCBS users according to whether they lived with parents/relatives or elsewhere yielded a consistent picture. Loneliness, being afraid at

home, feeling happy, and liking where they lived all yielded significantly more positive outcomes for those living with family. These findings provide support to, or at least may alleviate concern about the growing trend to fund family-based services to support adults with ID/DD to continue living with their family. Interestingly, those living with family did report one negative outcome. Individuals who received in-home support from paid staff (only about a quarter of those living with family did so) reported that staff members were not as nice and polite as did those who lived elsewhere. It is not clear why this was the case, but it is possible that, compared to family members who are constant in the person's life, individuals with ID/DD may feel less comfortable with paid staff. Overall, the well-being and satisfaction findings reported here are consistent with providing residential support in settings and to individuals living with family, but attention needs to be paid to people's loneliness.

The relations examined among choice scales and various disability characteristics yielded some interesting patterns. In a general sense, the presence of more severe levels of ID or co-occurring conditions (with the exception of HCBS and ICF/MR recipients who have dual diagnosis) were associated with less choice and control over one's life. The results seem to be accentuated for ICF/MR service recipients. Following level of ID, the ability to communicate verbally showed the strongest associations with making choices. This was to be expected given that verbal ability and overall level of disability are strongly related. Even so, this finding suggests that more attention could be directed toward enhancing and supporting opportunities for people who lack verbal communication skills to express their preferences and wishes.

Relationships with friends and family were generally not related significantly to disability characteristics, except that people with a dual diagnosis were significantly less likely to see friends and family. These individuals may be particularly vulnerable to social isolation. People with challenging behavior were less likely than those without challenging behavior to live in settings with 1-3 people, and more likely to live in settings with 4 or more people. One question that unfortunately cannot be answered using this data set is how many people with behavioral challenges live with other individuals who also need behavioral supports. It has been suggested that behavioral supports are more effectively (and more cost-efficiently) implemented in non-congregate settings (i.e., settings with few if any other service users with challenging behavior) and to that end national public policy in the United Kingdom advises that people with challenging behavior should not be placed together in congregate settings. Individuals with challenging behavior also experienced poorer outcomes in relation to choice, community inclusion and having a home of their own. That is, beyond the negative direct effect of challenging behavior, individuals with such behavior also lived in larger congregate settings and had poorer outcomes in important areas. Finding ways for people with challenging behavior to experience more individualized living arrangements and better outcomes continues to be an important policy and service priority. It is one that is often exacerbated by actual or perceived demands of maintaining substantial 24-hour staff-to-resident ratios and the financial difficulty of holding those ratios constant as the number of people in the home decreases. The examination of challenging behavior is clearly an important aspect of studying the impact of specific disability characteristics on the achievement of personal outcomes and

access to services.

It was noted that reported use of routine medical and dental services was less than generally recommended. A reported 7.5% of sample members had not had routine physical exams in the past year and about a quarter of the adult women in the sample had not had an OB/GYN exam in the past year. Access to routine dental services appeared farthest from recommended standards with about 35% of the sample reported to not have had a dental exam in the six months. In all three areas of routine preventative health care, the ICF/MR residents had higher rates of access than did the HCBS recipients.

This study computed and compared expenditures for HCBS and ICF/MR services for a sample of 1,421 adults with ID/DD in four of the six sampled states. HCBS and ICF/MR expenditures were computed from payment records for individuals in the 12 months prior to a comprehensive interview with individuals and caregivers focused on individual characteristics, programs, quality of life and services and other data. These 12 month periods varied by state but fell between January 2003 and December 2005. To adjust for higher average expenditures for "other" Medicaid expenditures among HCBS recipients (\$7,363) than among ICF/MR recipients (\$2,097), "other Medicaid expenditures" were added to HCBS and ICF/MR program expenditures in each individual record. In order to be able to make comparisons that included individuals who spent less than a full year in an HCBS or ICF/MR program, an annualized expenditure was computed based on average monthly expenditures for services in the program in which he/she was participating at the time of the interview. It should be noted that cash payments to sample members from Social Security Act programs (S.S.I. and S.S.D.I.) were not included in expenditure analyses because they were unavailable and outside the realm of Medicaid.

The findings of the analyses indicated that HCBS services, including other Medicaid services, were substantially less costly than ICF/MR services. The differences were not only evident in overall average expenditures (\$61,770 for HCBS recipients as compared to \$128,275 for ICF/MR recipients), but were evident in virtually all comparisons for individuals with similar characteristics. For example, the average annualized expenditures for persons indicated to have profound intellectual disabilities were \$80,626 for HCBS recipients as compared to \$134,918 for ICF/MR recipients. A major contributing factor to lower expenditures for adults receiving HCBS were the substantially lower total expenditures for adults who were living with parents or other relatives (average annualized expenditures of \$25,072) and adults who were living in host family (companion, foster, shared living) arrangements (average annualized expenditures of \$44,112). By definition all ICFs/MR were congregate/agency operated settings. About half of the HCBS sample members (50.6%) also lived in settings defined as congregate/agency operated. Expenditures for adult HCBS recipients in congregate/agency operated settings were slightly above average for HCBS recipients (\$63,286), but still much less (50.7% less) than the average expenditures for persons living in ICFs/MR. There much stronger differentiation in HCBS expenditures by personal characteristics than was evident for ICF/MR recipients, suggests that HCBS expenditures are much more strongly needs based (i.e., related to individual service-

user characteristics that determine support needs).

Comparing expenditures for HCBS and ICF/MR services is confounded by the differences in the characteristics of the samples (and represented populations) that was noted above. For example, the average expenditure for adults with profound ID within the total sample (\$97,921) was 38.7% more than the average expenditure for all sample members (\$70,601) and 85.1% above the average expenditure for persons with mild or no ID (\$52,888). At the same time 60.8% of ICF/MR residents, but only 20.4% of HCBS recipients had profound ID; and only 9.5% of ICF/MR residents, but 39.2% of HCBS recipients had mild or not ID. These confounding relationships were evident in a number of correlations between ICF/MR residency and factors associated with expenditures, e.g., level of ID (.35), frequency of medical care needed from nurses of physicians (.58), and being non-ambulatory (.24).

To examine the extent to which such factors in combination could account for the variation in individual expenditures, and whether having done so, the ICF/MR program model would remain statistically associated with higher expenditures, ordinary least squares regression was employed. The resulting equation accounted for 57% of the variation in individual expenditures. Controlling for level of ID; health, physical and sensory limitations; behavioral, psychiatric and autism diagnoses; gender and age; and type of residence, ICF/MR was a statistically significant predictor of higher expenditures ($p < .001$). It did, however, after controlling for the many other variables related to cost, predict only an additional 3.3% of variation in expenditures.

Participating states were entered into the regression equation as individual dummy variables. The result indicated that, in addition to variation accounted for by all the different individual and program variables, state accounted for an additional 2.1% of the variability in expenditures. Beyond the differences attributable to people's support needs and the program models, it seems some states would simply appear to allocate higher levels of funding for services to persons with ID/DD. Although the regression analysis accounted for 57% of the variation in the annualized expenditures, it seems likely that higher predictability would have been attained with more precise gradations in the independent variables (e.g., there were only 4 levels of ID, 2 levels of ambulatory ability, no severity indicator for challenging behavior, simple diagnosis/no diagnosis indicators for psychiatric disability and autism, etc.).

While the findings of this study provide consistent evidence of the cost-effectiveness of the continuing to shift from ICF/MR to HCBS programs, they also suggest that access to HCBS continues to be differentially provided to people based on their degree of impairment. While there is a wide variety of options for supporting people with disabilities with HCBS, and these were clearly evident within the data, it was also evident that most Medicaid long-term services provided to adults with ID/DD were provided in congregate, agency-managed housing and center-based day programs.

While falling short of demonstrating major differences in the quality of services and experiences of adult HCBS recipients when compared with ICF/MR recipients, the study has supported the trend away from institutional (ICF/MR) and to home and

community supports (HCBS) for persons with ID/DD. It has identified consistent social benefits accruing to individuals and substantial financial benefits accruing to state and federal governments as part of the shift. It should be encouraging that national commitments to community support and inclusion made in ADA, the Olmstead decision, the President's New Freedom Initiative and other legislative sources; the policies promoted by CMS in its Real Choice System Change Grants, Money Follows the Person and other demonstrations; the policy and program directions taken by most states in recent years; and the public interest of cost-effective supports for persons with ID/DD appear to be fully compatible. Continued commitment by CMS to encourage continued HCBS development seems well-founded.

This study also demonstrates the importance of establishing and maintaining policy-relevant data sets with sufficiently large, representative and multi-state samples to address key topics and national commitments, with the capacity to attend to and control for important demographic and diagnostic subpopulations, service options within larger programs, and other research considerations. In this multi-state study of HCBS and ICF/MR recipients, outcomes and expenditures, data were obtained entirely from extant data sets that were merged for the purposes of creating a integrated data set of unique capacity. The National Core Indicators (NCI) data set provided detailed data on individual and program characteristics, and individual lifestyle, service outcomes and satisfaction. The NCI data were gathered by individual states participating in the NCI program of ongoing, state-specific evaluation. The expenditure data were derived from CMS payment files which were merged with NCI data for sampled individuals. This use of the extant data created a data set of substantial capacity at a small fraction of the cost of a study generating original data. CMS support for state efforts to gather outcome data using common instrumentation could yield a cost-effective data program for nationally-relevant research on key issues in Medicaid programs, while also supporting states in their own evaluation responsibilities. Whether through extant or original data collection, efforts within CMS to support ongoing research and evaluation of Medicaid programs for persons with ID/DD seems essential as total expenditures for the combined the HCBS and ICF/MR programs now exceed \$30 billion dollars per year and total beneficiaries exceed 550,000 persons.

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