

Medicaid Home and Community Based Services for Persons with Intellectual and Developmental Disabilities

Interim Report

Prepared for:

Centers for Medicare & Medicaid Services

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September 26, 2005

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I. EXECUTIVE SUMMARY

This study examined the efforts of selected states to implement Medicaid home and community-based services (HCBS) within the context of service systems that include Medicaid HCBS, Medicaid Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR), and to much smaller extents other Medicaid-financed services, to respond to the needs of and assurances made to people with intellectual and developmental disabilities (ID/DD). Using both state case studies and “consumer interviews” from the National Core Indicators (NCI) survey effort, this study examines the efforts and accomplishments of states in responding cost-effectively to needs of and commitments to people with ID/DD.

Among those receiving publicly funded services over last two decades, the settings for supports has shifted from larger facilities to primarily residences with three or fewer residents. Medicaid HCBS growth has been a major contributor to this shift. Since 1992, the number of Medicaid ID/DD HCBS users increased 300,000, up to over 500,000 total in 2004, while there are about 40,000 fewer ICF-MR users (146,000 to 105,000). There has been a corresponding significant growth in HCBS spending (\$1.7 to \$15.5 billion) with little change in ICF-MR spending (\$8.8 to \$11.9 billion).

The case studies conducted in Indiana, Kansas, Louisiana, New Jersey, Vermont and Wyoming revealed four common goals:

- Adults will have a right to live in typical community homes and enjoy normal daily lives;
- Services will be individualized to respond to personal needs and preferences with people playing an active, meaningful role in service planning;
- Services will increase and/or support community participation; and
- People’s health and safety will be protected.

The survey data for Alabama, Kentucky, Indiana, Oklahoma, Massachusetts and Wyoming revealed:

- More than 89% of those living in an agency apartment, with a parent or relative or host family said they liked where they lived
 - 83-86% in other community-based group settings liked where they lived
 - Only 71% in nursing facilities like where they lived
- Only about one-half picked who to live with
- 14% often or always feel lonely/ do not have anyone to talk with higher percentages in nursing facilities and other homes
- 7% feel afraid or scared at home most of the time or always, with higher percentages of those in group homes

And related to participant freedom:

- 62.9% picked staff who help them at home

- 89.5% chose what to buy with spending money
- 38.5% saw more than one home before moving
- 18.3% reported staff sometimes or always sought their permission to open their mail
- 17.5% had people enter their room without permission.

These data will be explored further in additional reports focusing on differences by outcomes by setting.

II. 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. In Fiscal Year 2004, nearly 26 billion of those dollars were spent for Medicaid Home and Community Based Services (HCBS) and for services in Medicaid Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR) meet the needs of about 530,000 persons with ID/DD.

The purpose of this study is to examine the efforts of selected states to implement Medicaid HCBS within the context of service systems that include Medicaid HCBS, Medicaid ICF/MR, and to much smaller extents other Medicaid-financed services, to respond to the needs of and assurances made to people with ID/DD. Using both state case studies and “consumer interviews” conducted with samples of Medicaid service users in six states and merged with Medicaid payments made on behalf of Medicaid sample members in four states, this study examines the efforts and accomplishments of states in responding cost-effectively to needs of and commitments to people with ID/DD.

Commitments to Persons with ID/DD

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.
- 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) 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))

This study was designed to explore the efforts and accomplishments of 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.

III. METHODS

Case Studies

The methodology for the six states case studies was described in the case study report already submitted to CMS (Lakin & Hewitt, 2001).

Consumer Interviews

The goal of the consumer interviews was to:

- Obtain valid and reliable individual outcome data on the lives of 3,000 subjects related to outcomes of personal and social importance as described above.
- To obtain sufficient individual and service-related descriptive data on each sample member to explore factors associated with outcomes.
- Obtain these individual outcome data from a comprehensive, representative, random sample of adult service users of sufficient size to yield reliable estimates of state performance, to permit analyses of important sub-samples within the data samples (e.g., racial/ethnic minorities).

- Obtain identical data from samples in six states using instruments of established reliability and validity in each sampled state to be able to examine the unique contribution of state to variations in individual outcomes (i.e., control living for individual differences statistically associated with those same outcomes).
- To obtain interview data through direct face-to-face contact to minimize threats to data validity associated with telephone interviews of persons with ID/DD.
- To obtain and use individual identifiers to permit merging of individual outcomes and descriptive data with Medicaid payments.

To achieve these goals within a budget that was not sufficient to permit face-to-face consumer interviews of 3,000 individuals in six different states, this project accessed an ongoing program known as the National Core Indicators (NCI). This project builds and analyzes data from a comprehensive six-state data set on the outcomes of services for persons with ID/DD created from the NCI. It selected six states with ongoing evaluation programs using the common data elements 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 merging of NCI Consumer Surveys from these six 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), and in four states the amounts spent for various types of Medicaid financed services.

Individual Outcomes Assessment

This 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 that is well-established as both valid and reliable, and that is accompanied by a well-developed 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.

The concept of individual outcomes is at the core of NCI. A majority of the Core Indicators are measured using protocols that obtain information directly from individuals receiving services. The training protocol strongly emphasizes the practice of giving every individual an opportunity to respond, and making sure the responses received accurately reflect the person's perspective, not the perspective of a friend, family member, or advocate.

The consumer interview consistently yields high response rates. Each year, the 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, Section II may be answered by someone who knows

the individual well on his or her behalf. The questions in Section I are more subjective, while the Section II items are more factual. The NCI program in its years of development has been tested in 22 states and more than 25,000 assessments of individual outcomes.

Consumer Interview Outcome Survey

The NCI consumer interview provides extensive information on individual characteristics, services, outcome, and satisfactions. Basic information on its content and psychometric properties follow.

Scale composition. The NCI Consumer Survey data set for each state includes individual records data collected on 400-800 individuals each. The individuals in each state's data set are randomly sampled within each state's population of persons with ID/DD receiving institutional, community and home-based services and supports. The NCI survey gathers individual and service setting data including a) demographic, functional, diagnostic, and medical conditions; b) health and social service utilization and needs (e.g., case manager involvement, type and amount of formal services received); and c) service setting and administrative data (e.g., residence type [own home, congregate, host family, family home], funding source, funding model [consumer-directed, agency-based], level of paid support in home). NCI outcome variables include: a) choice/control (e.g., in living arrangement, housemates, job/day activity, staff, service coordinators, daily schedule, purchases); b) integration (e.g., participation in a variety of community activities); c) work experience (e.g., type, hours, paid work); d) home life and satisfaction (e.g., length of time in home, satisfaction with home); e) relationships (e.g., friendships, family relationships); and others.

Scale 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 of the system. Draft items underwent extensive field-testing.

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. This study also addressed improvements in interviewer training.

Validity of interviews. The project uses a number of strategies to ensure that the data collected are valid. First, NCI project staff conduct a "train the trainer" session 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.

Subscale Testing. Four reliable subscales have been created and reported each year. The scale scores are computed by averaging the values of a number of items. 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 >0.70 .

Community inclusion. The Community Inclusion sub-domain is described as: "People use integrated community services and participate in everyday community activities." It is defined as the proportion of people who participate in everyday integrated activities in their communities and is measured by seven items from the consumer survey that are grouped together to create a composite "scale score" for Community Inclusion: a) go shopping, b) go out on errands or appointments, c) go out for entertainment, d) go out to eat, e) go to religious services, f) go to clubs or community meetings, g) exercise or play sports. An internal reliability test of the Community Inclusion scale resulted in a Cronbach's alpha = 0.76.

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 Support-Related Choices sub-domain is composed of five items. These items indicate whether people chose (or had some input in choosing) in 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. The second 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.

Service coordination. The Consumer Survey has three items related to service coordination: 1) The proportion of people reporting that service coordinators help them get what they need, 2) the proportion of people who know their service coordinators, and 3) the proportion of people who report that their service coordinators asked about their preferences. These make up the "Service Coordination" sub-domain. The internal consistency of the Service Coordination scale as measured by a Cronbach's alpha was 0.82.

Summary of Consumer Interview Data Elements

Chart 1 provides a summary of the various types of data elements and sample limitations of data elements and sample limits used in the consumer interview study.

Chart 1. Data Categories in the Consumer Sample Interview

Descriptive:	Demographic, functional, diagnostic, health
Service use:	Services used/needed, case managers, staffing, residential and day arrangements, consumer directed...
Service/lifestyle outcomes:	Participation in community, activities/settings, friendships, self-advocacy, "community inclusion," "support-related choice: and "personal decisions" and "service coordination quality" scales...
Samples include:	HCBS and ICF-MR, 18+ years

"Descriptive" data elements include demographics 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, choices of services, service sites and service providers, use of consumer direct options, HCBS or ICF/MR financing of services. **Service and lifestyle outcomes variables** include measure 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. Persons sampled for consumer interviews were 18 years or older and recipients of either HCBS and ICF/MR financed supports.

State Selection

The decision to adopt the NCI consumer interviews occurred subsequent to the completion of the initial case studies. This decision was made to avoid the high cost of a large number of face-to-face interviews, the doubtful reliability of the phone interviews methodology used in the Aging/Disabled component of this study\ for those with ID/DD and the established record, reliability and validity of the NCI interview protocol. In moving from the six case study states' efforts were made to select states that were geographically similar and that had similar orientations toward HCBS and institutional services. Because two of the case study states were also NCI states they were retained in the state sample. *Chart 2* summarized selections.

Chart 2. States Participating in State Case Study and Consumer Interview Studies

National Core Indicators	
~22 states use all or part for all or some service recipients	
~Nine states select NCI sample across all setting and use common instrument	
~Selected 6 states using entire Consumer Survey in all settings	
Indiana	→ Indiana
Kansas	→ Oklahoma
Louisiana	→ Alabama
New Jersey	→ Kentucky
	(72% v. 71% in HCBS: HCBS\$: \$46,600 v. \$48,200)
Vermont	→ Massachusetts
Wyoming	→ Wyoming

States selection for inclusion in the consumer interview study was based on the following criteria: a) they were among the 22 states in which NCI surveys are conducted on a random sample drawn from a population that includes all institution and community service recipients in the state; b) they provided regional variation; c) they represent relatively urban and relatively rural states; d) they represented states with variations in ethnicity; and e) they represent variability in the relative mix of institutional and community services. The states selected to participate in this study are: Massachusetts, Kentucky, Indiana, Alabama, Oklahoma and Wyoming.

Massachusetts. Massachusetts has 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 has been relatively slow in community service development over the past decades, but has demonstrated in recent years notable acceleration. This 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 service population.

Indiana. Indiana provides for an exceptionally large proportion of community service recipients in larger group homes, especially ones of 7 or more residents. It was relatively slow in taking advantage of Medicaid HCBS but has had a four-fold growth in the past three years. In 2004, the state conducted 787 Consumer Surveys.

Alabama. Alabama has made steady progress in deinstitutionalization, institutional closures, community service development and use of HCBS funding. 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, positive change since 1990. Initially propelled by a court case, Wyoming has in the past 15 years begun from scratch to develop a highly respected, well managed service system. It has one of the nation’s highest per capita access to services and few persons waiting for service. In 2004, a total of 401 Consumer Surveys were administered.

Sample sizes. *Chart 3* summarizes the samples from the six states by size and white/non-white race.

Chart 3. State Samples

State	Race				Total N
	Non-white		White		
	N	%	N	%	
AL	150	37.7%	248	62.3%	398
IN	83	10.5%	704	89.5%	787
KY	37	7.3%	470	92.7%	507
MA	63	8.3%	697	91.7%	760
OK	80	20.0%	321	80.0%	401
WY	14	3.5%	387	96.5%	401
Total	427	13.1%	2827	86.9%	3254

*May not equal total above because of missing race variable on some interview records

Medicaid Payments

Medicaid payments were matched to consumer interviews for Medicaid services users in four states: Alabama, Kentucky, Oklahoma and Wyoming. The consent forms developed in Massachusetts and Indiana for the NCI consumer reviews precluded identifying interviewees for the purpose of matching them with their payments for further research. In Alabama, Kentucky, Oklahoma, and Wyoming Medicaid payments recorded in the CMS MSIS payment files were attributed to Medicaid HCBS and ICF/MR services users for the 12 months prior to the NCI consumer interviews. The prior 12 months was counted back from the mid-point of the period during which interviews were conducted in each state (periods ranging from 1 to 3 months). Mid-points varied from December 15, 2002 (Wyoming) to September 1, 2004 (Alabama).

Matching of NCI sample members and MSIS files was based on Social Security number, Medicaid number or a state code derived from the Medicaid number. When state-specific codes were used matches were confirmed by the date of birth variable appearing in both the NCI and MSIS records. States provided codes required for such matches. States also provided assistance in matching state-specific procedure codes with common, cross-state service categories to permit uniformity across state in expenditure categories. The service categories used for persons with ID/DD were: 1) residential

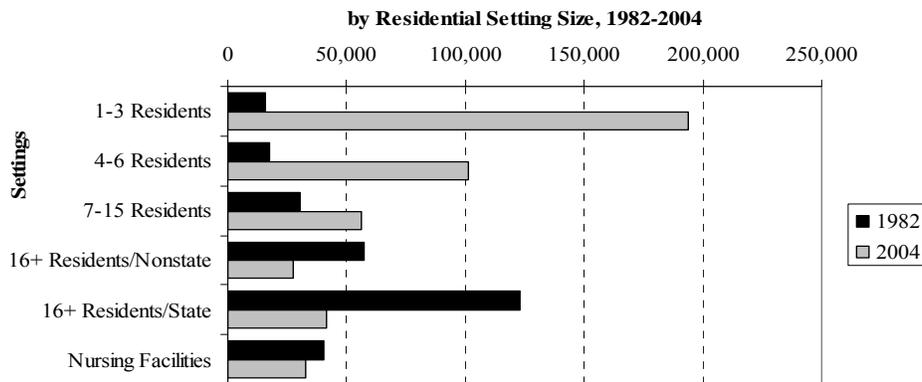
services, 2) personal assistance, 3) respite care, 4) day/vocational service, 5) therapy services, 6) environmental modifications, 7) supplies and equipment, 8) transportation, 9) training, 10) case management, 11) health services (health services beyond the state services) and 12) other. Once merged that identifier was stripped so that the new system file will include no individual identifiers or any information that permits the identification of a particular individual.

IV. CONTEXT

Changing Patterns in Services for Persons with ID/DD

Movement from institutions to community. *Chart 4* shows how substantially the settings of residential and related supports for persons with ID/DD have changed from the year (1982) when HCBS-financed supports first became available. Between June 1982 and June 2004, the number of people receiving paid support while living in homes of three or fewer persons with ID/DD increased from 15,700 to 193,900; the number in settings with four to six residents with ID/DD increased from 17,500 to 101,000 persons. In contrast, between 1982 and 2004 persons with ID/DD in public institutions of 16 or more residents decreased from about 122,750 to 41,650 and persons with ID/DD in private institutions decreased from 57,400 to about 27,500.

Chart 4. Changes in Primary Settings of Residential Supports for Persons with ID/DD After the Creation of Medicaid HCBS, June 1982 to June 2004

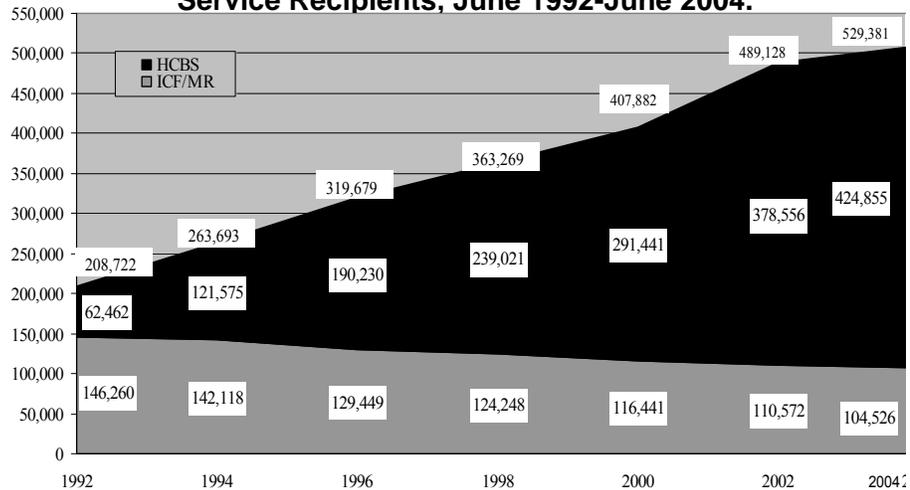


Year	1-3 Residents	4-6 Residents	7-15 Residents	16+ Residents/Nonstate	16+ Residents/State	Nursing Facilities
1982	15,702	17,486	30,515	57,396	122,750	40,538
2004	193,931	101,065	56,058	27,495	41,653	32,899

Medicaid HCBS contributed substantially to such shifts. Even though these shifts began before 1982 and were supported between 1982 and 1992 by Medicaid HCBS financing. The shifts toward small community settings accelerated after 1992.

Growth and shifts in HCBS and ICF/MR. 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. Beginning in the early 1990s, requirements that states demonstrate reductions in projected ICF/MR residents and expenditures roughly equal to requested

Chart 5. Changes in Medicaid HCBS and ICF/MR Service Recipients, June 1992-June 2004.



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 5* 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 424,900 in June 2004. During the same period there has been steady, although much notable, decreases in the numbers of persons living in ICFs/MR. In June 1992 there were 146,260 ICF/MR residents nationwide; by June 2004 ICF/MR residents had decreased to 104,526. During the 1992-2004 period the combined total of Medicaid HCBS and ICF/MR recipients with ID/DD grew by more than 150%, from 208,700 to 529,400 persons.

Chart 6 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 2004.

Between 1992 and 2004 annual federal and state expenditures for Medicaid HCBS and ICF/MR services for people with ID/DD increased from \$10.485 billion to \$27.436 billion.

Chart 6. Changes in Medicaid HCBS and ICF/MR Expenditures, June 1992-June 2004

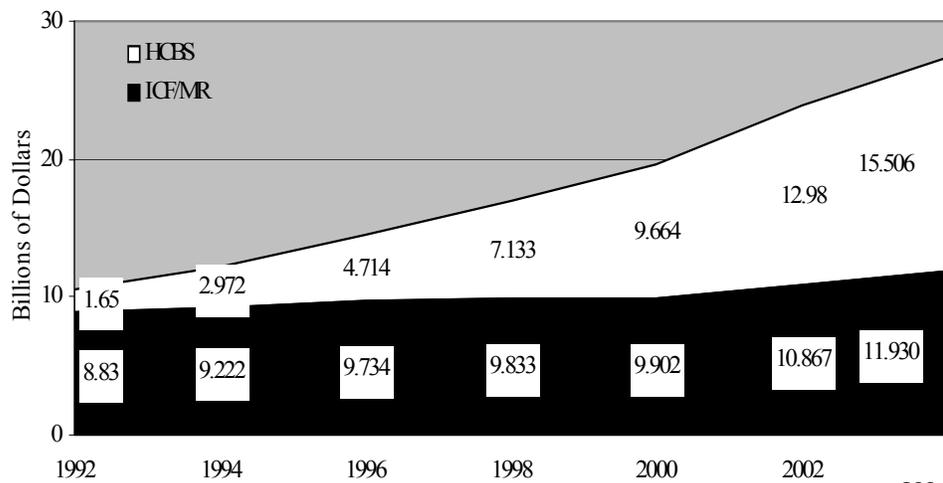
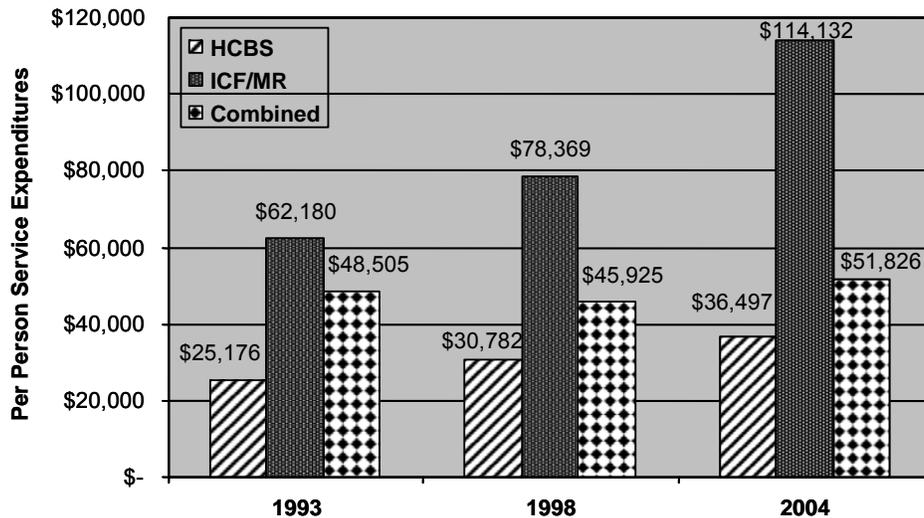


Chart 5 shows how growth in HCBS expenditures made up most (82%) of the growth in combined expenditures. It is, however, notable that ICF/MR expenditures increased by \$3.1 billion (35%) over the period, even as total ICF/MR recipients decreased by 29%.

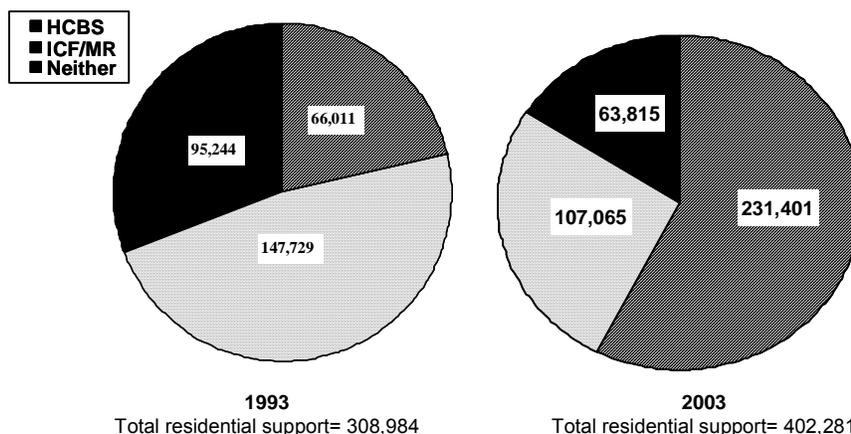
Effects on per person expenditures in HCBS to ICF/MR shifts. *Chart 7* shows the changes in average per recipient HCBS and ICF/MR expenditures from FY 1993 to FY 2004. The computations are based on Fiscal Year expenditures divided by the number of enrollees on June 30. Even though over the 1993-2004 period, per person expenditures for both HCBS and ICF/MR increased substantially (by 45.0% and 83.6%, respectively), with the notable shift from ICF/MR to HCBS, the combined per person average expenditure increased by only 6.8%. Controlling for CPI inflation by expressing 1993 expenditures in 2004 dollars, between 1993 and 2004 average per person increases were 13.2% for HCBS (from \$32,232 to \$36,497) and 43.4% for ICF/MR (from \$79,606 to \$114,132), while combined program average per person expenditures actually decreased by 16.5% (from \$62,096 to \$51,825).

Chart 7. Average Annual Medicaid Expenditures Per Recipient of HCBS, ICF/MR and Combined Programs FY 1993 to FY 2004



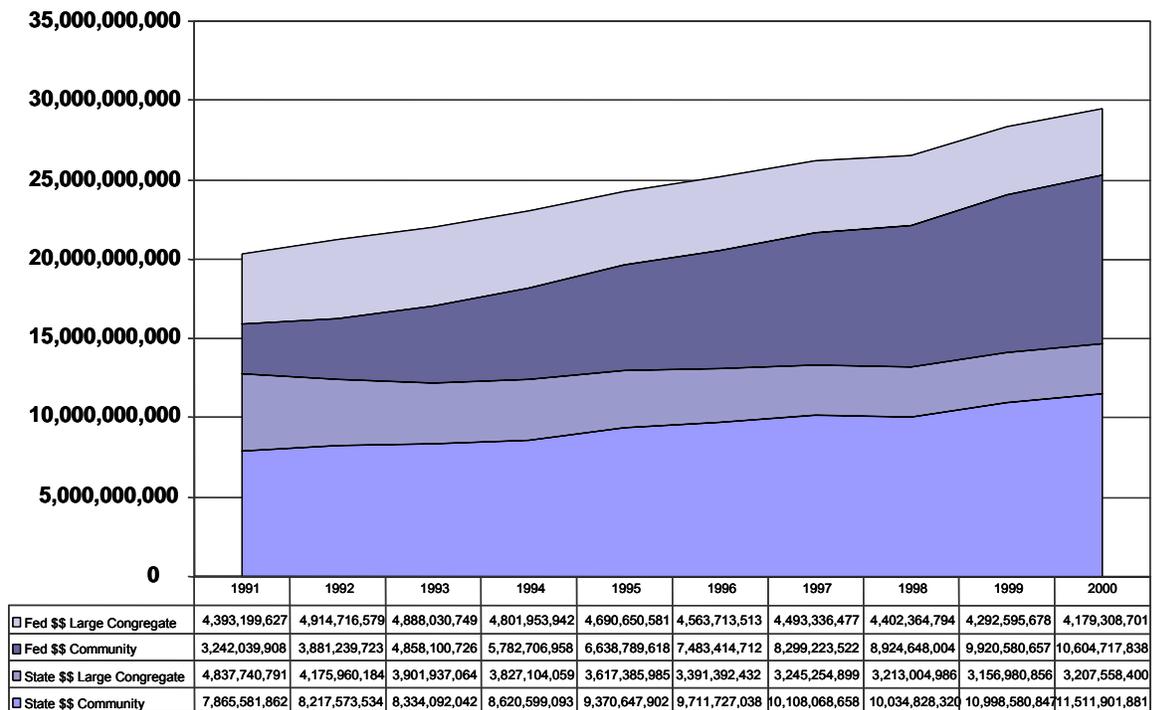
Growth in the Medicaid coverage of services for persons with ID/DD. *Chart 8* presents estimates of the extent to which residential supports provided to persons with ID/DD (defined as supports to people not living with parents or other family members) were financed by HCBS and ICF/MR programs. The chart shows both the increasing role of HCBS in financing residential supports for persons with ID/DD (from 21.4% in 1993 to 57.5% in 2003), and the increasing role of Medicaid in general financing residential supports for persons with ID/DD (from an estimated 69.2% in 1993 to 84.1% in 2003). During that period the number of persons with residential services not financed by Medicaid HCBS or ICF/MR programs decreased by about 31,400 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 10 year period, the total number of persons enrolled in HCBS and ICF-MR increased by about 124,700 persons.

Chart 8. Numbers and Proportions of Persons with ID/DD Receiving Medicaid-Funded Supports, 1993-2003



The challenge of raising state funds. Most states already had substantial social and financial commitments to community services prior to the creation of the federal HCBS program. States continued to develop community services after the HCBS option became available even though, until the early 1990s, much of that development could not be financed by Medicaid HCBS. As Medicaid HCBS development was detached from ICF/MR reductions in the early 1990s, the HCBS program began not only to be used to develop new services, but to cost-share previously existing state financed services. *Chart 9* shows graphically the substantial impact on overall federal and state expenditures that derived primarily from the greater flexibility available to states to use HCBS. The statistics in *Chart 9* are from unpublished data of the University of Colorado Coleman Institute’s national longitudinal study of state expenditures for institutional and community services (Braddock & Hemp, Rizzolo, Hemp, Braddock, & Pomeranz-Essley, 2004). It defines expenditures for “large congregate care” as those for people in programs with 16 or more participants, and “community” as those for people in programs serving 15 or fewer individuals. The data presented in *Chart 9* are adjusted for the inflation to 2000 dollars. The top two bands in *Chart 9* reflect federal expenditures for services for persons with ID/DD (congregate on top and community below) The bottom two bands reflect state expenditures for services for persons with ID/DD (again congregate on top, community below). The effects of the greatly expanded access to HCBS financing are readily evident. During the 1990s, states made substantial efforts to obtain federal matching funds through HCBS for both new services and for programs previously financed with state funds. As a result, between Fiscal Year 1991 and Fiscal Year 2000 federal contributions for community services increased 227.1 percent in real terms (an increase of \$7.36 billion) as compared substantial, but much lower real dollar increases of 46.4 percent in state expenditures for community services (a still very substantial increase of about \$3.65 billion). Between Fiscal Year 1991 and Fiscal Year 2000 inflation-controlled state and federal services expenditures for persons with ID/DD increased 45 percent from \$20.34 billion to about \$29.50 billion.

Chart 9. U.S. Total and Federal Inflation Adjusted (2000) Expenditures for Services for Persons with Developmental Disabilities, Fiscal Years 1990-1991 through 1999-2000



Over this same period, total state expenditures (in 2000 dollars) increased from \$12.70 billion to \$14.78 billion (93.5 percent). So from the perspective of states, during the 1990s, HCBS and related community services expenditures were controlled primarily through a process of increasing the extent of federal cost sharing of community services expenditures. Issues of reimbursement methodologies and other cost containment approaches were secondary among approaches to manage the growth and efficient use of state funds. By FY 2001 many states had taken advantage of most of their latitude in bringing existing services into Medicaid and where required to raise new funds for the state matches. Despite these new challenges and the substantial budget problems forced by most states after 2001, through effective advocacy Medicaid HCBS programs continued to grow in numbers and expenditures in most states.

General Findings from Case Studies

The details of the case study methods and funds were reported in a report in 2001 (Lakin & Hewitt, 2001). In this section we summarize a few of these findings as they relate to outcomes and satisfaction with Medicaid services.

State goals. The case study portion of this project, examined the goals of states for their services for persons with ID/DD, and the extent to which these goals were congruent with the national goals described earlier. *Chart 10* summarizes the most frequent of those goals. As shown the goals of state HCBS/community services programs were consistent with national goals established in the ADA, Olmstead, the New Freedom Initiative and other national sources. States identified a total of 18 different goals for the

HCBS/community service systems. It should be noted, however, that the establishment of a goal did not necessarily reflect its achievement. The one state with an established

Chart 10 This Study Have Established Goals for HCBS That Are Consistent with National Goals and With Each Other

Almost all state identified 4 common goals:

- Adults will have the right to live in typical community homes and enjoy normal daily lives
- Services will be individualized to respond to personal needs and preferences with people playing an active, meaningful role in service planning
- Services will increase and/or support community participation in preferred activities
- People's health and safety will be protected

States identified 18 different goals

goal to: "Provide needed services in a prompt manner" reported a waiting list of about 2,500 people. On the other

hand, it is notable that the states involved in this study had made a commitment to assess the extent to which they were achieving the goals that they articulated for their HCBS/community service programs.

Significant challenges noted in HCBS development.

It was noted in the studies that states had encountered a number of challenges associated with the rapid expansion of their HCBS/community service programs. The rapid growth in service recipients was noted as creating notable stresses in

a number of areas related to consumer outcomes and satisfaction ranging from direct support staff recruitment, retention and training for frequency of visits and coverage within quality assurance programs. The rates of growth among case study states between 1996 and 2004 are summarized in *Chart 11*. Chart 11 shows the general similarities among the case study and consumer interview states, and also how both sets of states experienced very rapid growth in HCBS programs between 1996 and 2004. As a group the 6 case study states added 59.7% of their total 2004 HCBS recipients after FY 1996. The 6 consumer interview survey states added 54.0% of their total 2004 HCBS recipients after FY 1996. Among case study states HCBS expenditures increased by \$1.02 billion (174%) between FY 1996 and FY 2004; among consumer interview states, the increase was \$.98 billion (105%).

Chart 11. Changes in HCBS/Community Service Programs in Sampled States, 1996-2004

Area of Change	Case Study States			Consumer Interview States		
		2004	(Since 1996)		2004	(Since 1996)
Increase in HCBS Recipients	Indiana	9,307	(+8,491)	Indiana	9,307	(+8,491)
	Wyoming	1,576	(+712)	Wyoming	1,576	(+712)
	Kansas	6,457	(+3,311)	Oklahoma	4,220	(+1,960)
	New Jersey	8,455	(+3,213)	Kentucky	2,432	(+1,508)
	Louisiana	5,199	(+3,099)	Alabama	4,952	(+1,537)
	Vermont	1,957	(+850)	Massachusetts	11,388	(+3,361)
	Total	32,951	(+19,676)	Total	3	(+17,569)
Increase in HCBS Expenditures (In \$1,000)		2004	(Since 1996)		2004	(Since 1996)
	Indiana	\$295,771.20	(+272,309.9)	Indiana	\$295,771	(+272,309.9)
	Wyoming	\$67,460.70	(+38,202.2)	Wyoming	\$67,460	(+38,302.2)
	Kansas	\$206,001.00	(+134,432.1)	Oklahoma	\$216,911	(+111,922.8)
	New Jersey	\$380,018.00	(+225,050.0)	Kentucky	\$121,821	(+96,099.8)
	Louisiana	\$210,067.10	(+167,702.1)	Alabama	\$188,908	(+143,218.4)
	Vermont	\$231,967.00	(+181,487.9)	Massachusetts	\$564,725	(+316,325.7)
Total	\$1,391,285.00	(+1,019,184.2)	Total	\$1,455,599.00	(+978,178.8)	

Quality assurance/improvement resources vary among states. In state visits, a number of factors were identified as important to the relative effectiveness of quality assurance/quality improvement efforts. These are summarized in *Chart 12*.

Chart 12. Factors Associated with Quality Assurance Effectiveness as Identified by Advocates, Providers and Service Users

Challenges in Support	
<ul style="list-style-type: none"> ■ Case management viewed as core of quality assurance resources (ratios from 1:12 to 1:80) ■ Everybody in government in the quality business ■ Everybody in government knew the product in action ■ Value-based definition of quality and structure to assessment ■ People in QA had status, recognized expertise and commitment 	<ul style="list-style-type: none"> ■ No one employed exclusively as quality inspector; all available for QI ■ People in quality review respected because process was respected ■ Providers challenged by quality review and found validity in them ■ Observations/recommendations of QA were integrated into policy decisions ■ Periodic independent consumer satisfaction and/or service assessments

Although case management was universally viewed as a key component of quality assurance, great differences exist among states in the average case management ratio. Among the six states in the sample the range was from 1:12 to 1:80 service recipients. In addition there was substantial variety in the employers of case managers (state or local government, independent private case management providers, and private agencies

providing direct services). States varied considerably in the nature and extent of commitment to quality assurance and improvement. Systems seemed more effective and respected when administrative authorities participated actively and visibly in quality assurance and when the state quality assurance personnel were experienced in service delivery, knowledgeable about delivery, invested in by the state to become increasingly expert about service delivery, had a direct involvement with and technical assistance role with agencies outside the monitoring process. Conversely quality assurance was considered less effective and was less respected when conducted by officials whose only function was monitoring, who were not able or not expected to provide assistance in improving service delivery (other than requirements of correcting non-compliance with regulations), whose knowledge and expertise were not invested in by the state. Quality assurance was more viewed as effective and respected when information gathered in quality assurance/monitoring visits was integrated into statewide or regional initiatives around staff development, innovation practices, and/or policy change. Quality assurance practices that included systems of consumer interviews were more likely to be found in quality assurance systems that were viewed as more effective and respected, but the specific application and status of consumer interview data in quality assurance was not well established among states conducting interviews with service users.

Recruitment retention and training of direct support personnel. *Chart 13* identifies the shared goals of the case study states and the problems identified in securing sufficient numbers and quality of DSP to achieve those goals. Among those problems were high turnover rates, ranging from 40% to 70%, and averaging about 50%. Challenges were evident in recruiting enough new personnel to fill vacancies, with reported vacancy rates averaging between 5% and 17%. Wages on average were \$8.68 per hour for DSWs, approximately equal for one full-time worker to the national poverty rate for a family of 4 in 2001. The increasing degrees of responsibility and autonomy of DSWs in the smaller residential settings made supervision, mentoring and support spread over ever-growing numbers of work sites. To meet the demand of securing sufficient numbers of DSWs service providers relied increasingly on part-time workers and other non-traditional employees, including persons from different cultures than those being supported and non-native English speakers. These factors and the growing presence of persons of all levels and types of disability conditions added further complexity to the training, supervision and support of DSWs in assisting people to achieve the goals that they states held for their service programs and the outcomes that individuals and families held for their supports and their lives.

Chart 13. Finding, Training and Keeping Direct Support Workers Challenges the Realization of State Goals

Goals	Challenges in Support
<ul style="list-style-type: none"> ■ Living in typical homes ■ Enjoying normal lives ■ Services individualized to personal needs and goals ■ Playing active meaningful roles in our service planning ■ Increased support for community participation in preferred activities ■ Protecting health and safety 	<ul style="list-style-type: none"> ■ High turnover (average= 40%-70%) ■ Recruitment/vacancy difficulties ■ Low wages (average \$8.68) ■ High degrees of autonomy and responsibility, and low degrees of supervision of inexperienced staff ■ Increasing use of part-time, odd-hour employees ■ Greater employment of persons from different cultures and speaking different languages ■ People with more complex support needs living in the community ■ Difficulties in providing training in widely dispersed settings

V. INITIAL ANALYSES OF NATIONAL CORE INDICATORS DATA

Summary statistics selected characteristics. *Chart 14* presents a few summary statistics on the sample members from the 6 NCI states. Sample sizes were about 400 individuals each in the 4 less populous states and 800 persons each in Indiana. Kentucky’s entire NCI sample included 507 individuals but only 408 were participants in HCBS and ICF/MR programs. In general the individual state samples were similar in age, ranging from an average of 40 years in Oklahoma to 45 years in Indiana. The majority of sample members were male in all samples states, ranging 52.0% in Wyoming to 58.8% in Massachusetts.

Chart 14. Characteristics of the Samples in the Six States

State	State Sample*	Age	% Male	% w/CP	% Seizure	% Psychiatric
AL	402	42	52.9	11.3	21.6	19.8
IN	787	45	56.8	16.1	25.4	24.8
KY	507	41	57.6	17.1	26.4	36.8
MA	766	43	58.8	13.9	24.1	29.4
OK	401	40	57.6	14.7	33.2	27.7
WY	401	41	52	10	13	33.4
Total	3264	42yrs	55.9%	13.8%	23.9%	28.6%

About 14% of sample members were reported to have cerebral palsy and 24% were reported to have a seizure disorder. Wyoming’s sample reported an unusually low proportion (13.0%) with seizure disorders; Oklahoma’s was notably higher (33.2%) than

average. Psychiatric disabilities were reported by 28.6% of the combined samples, with rate ranging from 19.8% in Alabama to 36.8% in Kentucky.

Level of intellectual disability. *Chart 15* summarizes the level of intellectual disability reported for the sample members in each state. Substantial variation is noted across states. About 39.2% of the combined samples were reported to have mild intellectual disabilities, with a range from 51.6% in Wyoming to 26.9% in Alabama. About 13.8% of sample members were reported to have profound intellectual disability, with a range from 7.6 in Massachusetts to 21.9% in Oklahoma. About 2.3% of sample members are reported not to have intellectual disability with the highest proportion in Wyoming (6.5%). Level of intellectual disability was unreported/not known for 4.7% of the combined samples.

Chart 15. Level of Intellectual Disability Among Sample Members by State

State	# in State Sample*	Mild	Moderate	Severe	Profound	None	Don't Know
AL	402	26.9%	32.6%	20.6%	18.7%	0%	1.2%
IN	787	42.3	24	12.3	13.7	3.2	4.4
KY	507	30	30	16.6	16.8	2.2	4.5
MA	766	42.8	26.9	14.9	7.6	1.3	6.5
OK	401	37.7	18.5	14.2	21.9	0.5	7.2
WY	401	51.6	20.4	9.5	9.5	6.5	2.5
	3264	39.2%	25.6%	14.5%	13.8%	2.3%	4.7%

Selected Choice and Satisfaction Findings by Residence. *Chart 16* presents selected reports of choice and satisfaction by sample members type of living arrangement. With regard to people liking where they live (72.7% of the sample being able to report), 89.3% reported they did. Persons in apartments, host families or living with parents or relatives reported the highest satisfaction. Persons living in places identified as nursing facilities were least likely to be satisfied (71.4% compared with an average for all respondents of 89.3%). Persons in nursing settings were also most likely to report they had no involvement in choosing the people they were living with (77.3% as compared with an average of 50.5%). Persons living in their own home/apartment and persons living with at least one other person with a disability in the home of a parent or other family member were least likely to report they had no involvement in choosing the people they live with. Fourteen percent (of the 63.1% of the sample able to respond) said they always or often felt lonely. Persons in nursing facilities were most often to report loneliness. About 7% (of the 69.8% of the sample able to respond) indicated feeling afraid in their home always or most of the time. Fear was most often reported by group home and “other home” residents (about 11%).

Freedom, independence, and respect of sample members. *Chart 16* summarizes the responses of the sample members able to respond about various aspects of freedom, independence, and respect in their lives. About 63% of respondents reported having participated in choosing the staff who support them in their home. State average varied from 60.9% to 65.6%.

Chart 16. Choice and Satisfaction Among Sample Members with Selected Aspects of Daily Life

Question	Specialized Facility	Group Home	Agency Apt	Own Home/Apt.	Parent or Relative	Host Family	Nursing Facility	Other Home	Total
Do you like where you live? – “Yes”	85.4	82.6	92.2	88.6	96.9	93.2	71.4	86.2	89.3 (72.7%)*
Did you choose (or pick) the people you live with? “No, someone else chose”	74	59.4	45.4	21.2	38.1	48.6	77.3	62.9	50.5 (67.2)*
Do you ever feel lonely, like you don’t have anyone to talk to? “Always or often”	16.2	15.9	9.7	13	10.6	12	25.8	25.9	14.1 (63.1%)*
Are you ever afraid or scared when you are at home? “Yes, always or most of the time”	8.5	10.6	4.7	4.3	5.2	6.6	3	11.5	6.9 (69.8%)*

About 89.5% reported being able to choose what they buy with their own spending money, with very little variation among states (89.1% to 90.8%). Only about 38.5% of sample members (excluding those living at home) reported having seen more than one alternative home before moving into their present home. This had a wide variation from state to state (from 19.3% to 48.3%). Nearly 1 in 5 (18.3%) service recipients reported that their mail is sometimes or always opened without their permission and 17.5% of sample members reported that people entered their room without permission. These intrusions on privacy had little variation across states.

Chart 17. Sample Members Responses About Various Aspects of Freedom,

Item	Percent	State Range
Proportion of sample who picked staff who help them at home	62.90%	89.1%-90.8%
Proportion of sample who chose what to buy with spending money	89.50%	89.1%-90.8%
Proportion of sample (not living with family) who saw more than one home before moving	38.50%	19.3%-47.8%
Proportion of sample who report their mail opened with permission (sometimes/always)	18.30%	17.0%-19.4%
Proportion of sample who reported that other people enter their room without permission	17.50%	17.2%-18.5%