

Satisfaction and Sense of Well Being Among Medicaid ICF/MR and HCBS Recipients in Six States

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Abstract

Self-reported satisfaction and sense of well-being were assessed in a sample of 1,885 adults with intellectual and developmental disabilities receiving Medicaid Home and Community Based Services (HCBS) and Intermediate Care Facility (ICF/MR) services in 6 states. Questions dealt with such topics as loneliness, feeling afraid at home and in one's neighborhood, feeling happy, feeling that staff are nice and polite, and liking one's home and work/day program. Loneliness was the most widespread problem, and there were also small percentages of people who reported negative views in other areas. Few differences were evident by HCBS and ICF/MR status. The findings document consistent benefits of residential support provided in very small settings—with choices of where and with whom to live—and to individuals living with family.

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In the last 15 years, there have been several notable trends in residential services for people with intellectual and developmental disabilities in the United States: (a) growth of Medicaid Home and Community Based Services (HCBS) and decline of Intermediate Care Facility (ICF/MR) services, (b) a steady decrease in the average size of out-of-home residences, (c) marked growth in HCBS recipients living with family members, and (d) an increase in supported living.

Nationally, HCBS recipients with intellectual and developmental disabilities grew from about 62,500 in 1992 to 443,600 in 2005. During the same period, ICFs/MR populations decreased from 146,260 residents nationwide in 1992 to 101,800 in 2005 (Prouty, Smith, & Lakin, 2006). In 1992 there was an average of 5.9 persons with intellectual and developmental disabilities per nonfamily residential setting; in 2005 this number was 2.7, with 45% of service users living in households of 1–3 people (Coucovanis, Prouty, & Lakin, 2006b). In 1994, there were 29,100 HCBS recipients (23.8% of the total) living with family members (Prouty & Lakin, 1995), but by 2005 there were 201,842 (45.5% of the total; Prouty et al., 2006). Growth in supported living is more difficult to

quantify. One approach has been to count the number living with support in a home they own or rent. In 1998, there were 62,669 people living in their own home (Anderson, Polister, Prouty, & Lakin, 1999). By 2006, this number had increased to 101,143 (Coucovanis, Prouty, & Lakin, 2006a).

Each of these important trends warrants careful evaluation regarding its benefits to service recipients. In doing so, this article examines self-reported satisfaction and sense of well being, including loneliness, feeling afraid at home and in one's neighborhood, feeling happy, whether staff members are perceived as nice and polite, and whether the person likes their home and their day program. Such subjective information likely can only be obtained validly from persons themselves, not proxies (Cummins, 2002), so this study examines self-report data from service recipients. There have been few large-scale examinations of such subjective, personal views of services among service recipients with intellectual and developmental disabilities.

ICFs/MR provide a regulated program of services in formally certified group settings, whereas HCBS permits a wide array of services that can be more flexibly tailored to individual needs and circumstances. HCBS may be provided in one's

family home, own home, a group setting, or other arrangement. This flexibility means that, in addition to ICF/MR versus HCBS comparisons, other policy-relevant comparisons within the HCBS program are of interest. For example, the effect of choice of where and with whom to live—an important characteristic of supported living (Howe et al., 1998)—has rarely been evaluated. Therefore, we compared self-reported satisfaction and sense of well being for (a) HCBS versus ICF/MR, (b) residence size (i.e., number of people with intellectual and developmental disabilities living in the setting), (c) persons who chose where and with whom they lived versus those who did not (excluding persons living with family members), and (d) among HCBS recipients only, those living with family members versus those living elsewhere. That is, we undertook comparisons of different sources of support, of settings with different characteristics, and of choice of living arrangements.

Many subjective elements of quality of life exhibit trait-like stability over time and are more influenced by individual temperament than external, objective circumstances (Cummins, 2002; Perry & Felce, 2005). People adapt to circumstances, even unfavorable circumstances, and their satisfaction and sense of well being remain reasonably stable over the long term. Subjective outcomes tend to have little or no relation to objective features of quality-of-service provision (Cummins, 2001; Perry & Felce, 2005). Satisfaction and sense of well-being are clearly important at an individual level, but their value in program evaluation and sensitivity to differences across programs and service settings are not well established. It is, nonetheless, impossible to regard such differences as unimportant. The nature of intellectual disability makes global questions about abstract concepts such as “satisfaction with services” difficult for service recipients to understand and respond to. This study used the National Core Indicators (NCI) consumer survey (National Association of State Directors of Developmental Disabilities Services [NASDDDS] & Human Services Research Institute [HSRI], 2002) as the data source. The NCI attempts to capture “satisfaction” with services and lifestyle by using concrete concepts and simple words that are readily recognized by respondents (e.g., “Are staff nice to you?”, “Are you ever afraid or scared when you are at home?”).

Controlling for individual characteristics and living environment variations, companion articles

to the present study have reported greater choice-making among HCBS recipients, and those living in smaller settings (Lakin et al., 2007) and more loneliness among residents of larger (7–15 residents) community settings (Stancliffe et al., 2007). Neither of these companion articles contrasted outcomes for those living with family members or not or for those who chose where and with whom to live or not.

Few published comparisons of outcomes for adults with intellectual and developmental disabilities of family and nonfamily living are available. Krauss, Seltzer, and Jacobson (2005) reported mothers’ views about adults with autism living with family or in nonfamily settings and identified security and happiness as benefits and social isolation as a negative feature of family living. Mothers noted more social contact and greater independence as perceived benefits and loneliness and reduced safety as negative features of nonfamily living. Burchard, Hasazi, Gordon, and Yoe (1991) compared adults with intellectual disabilities living in (a) their family home, (b) in supervised apartments, or (c) in group homes. Burchard et al. found that the family home and supervised apartment groups did not differ on residence satisfaction or personal well being, but both groups did significantly better than group home residents. These findings suggest that HCBS recipients living with family may experience more satisfaction than those in congregate residential settings.

Researchers have found that individuals in supported living who chose where and with whom to live tended to rate higher in other areas of quality of life (Emerson et al., 2001; Howe et al., 1998). Gardner and Carran (2005) found a consistent relation between the outcome “people chose where and with whom to live” and a number of other important outcomes, such as safety and freedom from abuse and neglect. Choosing where and with whom to live may be related to achieving other outcomes, so it seems possible that individuals who are able to choose may experience greater satisfaction and well being.

Method

Instrumentation

National Core Indicators Consumer Survey

Data were collected using the NCI consumer survey. The NCI was developed in collaboration by

the National Association of State Directors of Developmental Disabilities Services member agencies and the Human Services Research Institute (HSRI). It provides an instrument and methodology for the assessment of the outcomes experienced by persons with intellectual and developmental disabilities receiving long-term services. The NCI survey is composed of three sections: the Background section, Section I, and Section II. This study used data from the Background section and Section I.

The Background section requests data on the service user's personal characteristics, functioning, diagnoses, health, problem behavior, living arrangements, and services. These data are obtained from individual records and setting administrators or case managers. In addition to age and gender, the following characteristics are used in analyses in this article: (a) level of intellectual disability (46 individuals with developmental disabilities but no intellectual disability label were grouped with those with mild intellectual disabilities); (b) challenging behavior (persons exhibiting self-injurious, destructive, and/or uncooperative behavior at least once per day); (c) other identified condition (reported diagnosis of autism, psychiatric condition, or seizures/neurological disorder); and (d) care by a nurse or physician (reported to be required from less than once a month to 24-hr immediate access).

Section I of the NCI consumer survey asks the service user about his or her satisfaction–liking of home, feelings of safety at home and in the community, sense of loneliness, contacts with friends and family; and so forth. Section I must be completed by self-report through a direct interview with the individual with intellectual and developmental disabilities; proxy responses are not acceptable. This article focuses on eight items from Section I that ask about loneliness, feeling afraid at home or in the neighborhood, feeling happy, friendliness and politeness of staff (separate questions for home and work–day programs), liking home, and liking work–day program. The actual wording of each question and the response alternatives used to code answers are shown in Tables 1–8, so this information is not repeated here.

Interviewer training. To ensure that all interviewers received consistent training, the NCI Consumer Survey protocol is supported by a training program for interviewers, including training manuals, presentation slides, training videos,

scripts for scheduling interviews, lists of frequently asked questions, and picture response formats. The training included instruction in basic skills for interviewing persons with intellectual and developmental disabilities and question-by-question review of the survey tool.

Interviewer independence of service provision. In four states, contractors outside the service system conducted the interviews: families and people with disabilities, research organizations, and universities. State quality assurance staff were used in the other two states. That is, all of the interviewers were independent of the participant's service provider, and none were directly responsible for coordinating the person's services.

Reliability. Three tests of the NCI consumer interview in three different states yielded interrater agreement of 92%–93%. The single examination of test–retest reliability resulted in 80% agreement (Smith & Ashbaugh, 2001).

Sample

State Selection

State selection criteria for the present study included (a) providing regional variation; (b) representing urban and rural states; (c) including states with variations in ethnicity; (d) varying the mix of institutional and community services, and (e) using available data on residence size for each participant. Selected states were Alabama, Indiana, Kentucky, Massachusetts, Oklahoma, and Wyoming.

Individual Sample Selection

Sampling with states. State samples were randomly selected within each state's population of adults (age = 18+ years) with intellectual and developmental disabilities receiving institutional, community and home-based services. In each state, a minimum sample of 400 individuals was randomly selected. In the more populous states of Massachusetts and Indiana, samples of 800 were selected. In these analyses, sample sizes were reduced by including only persons who were HCBS or ICF/MR recipients and, among them, only the individuals who were able to understand and respond to the questions posed.

Availability of reliable self-report data on satisfaction and sense of well being. The items on satisfaction and sense of well being were answered by self-report of the person with intellectual and developmental

Table 1 Characteristics of HCBS and ICF/MR Participants in Interviews on Satisfaction and Well Being in Six States

Characteristic	HCBS–ICF/MR status						Sig.
	HCBS		ICF/MR		Total		
	<i>n</i>	%	<i>n</i>	%	<i>N</i>	%	
Age							$t = -4.04$
Average age (years)	42.53		45.77		43.08		$p < .001$
Gender							
% Male	864	55.5	184	56.6	1,048	55.7	$\chi^2 = 0.13$
% Female	692	44.5	141	43.4	833	44.3	$p = .72$
Total	1,556		325		1,881	100	
Level of ID							
None (DD only)	42	2.8	4	1.3	46	2.5	$\chi^2 = 110.15$
Mild	866	56.9	140	44.2	1,006	54.7	$p < .001$
Moderate	457	30.0	73	23.0	530	28.8	
Severe	126	8.3	66	20.8	192	10.4	
Profound	31	2.0	34	10.7	65	3.5	
Total	1,522		317		1,839	100	
Psychiatric diagnosis							
No	994	65.8	190	58.8	1,184	64.6	$\chi^2 = 5.64$
Yes	517	34.2	133	41.2	650	35.4	$p = .018$
Total	1,511		323		1,834	100.0	
Autism							
No	1,446	96.7	303	95.0	1,749	96.4	$\chi^2 = 2.30$
Yes	49	3.3	16	5.0	65	3.6	$p = .13$
Total	1,495		319		1,814	100	
Cerebral palsy							
No	1,324	88.3	274	85.9	1,598	87.9	$\chi^2 = 1.39$
Yes	176	11.7	45	14.1	221	12.1	$p = .24$
Total	1,500		319		1,819	100	
Seizure or neurological disorder							
No	1,180	78.7	231	72.4	1,411	77.6	$\chi^2 = 6.02$
Yes: disorder reported	319	21.3	88	27.6	407	22.4	$p = .014$
Total	1,499		319		1,818	100	
Vision level							
Sees well with or without lenses	1,445	92.9	293	90.2	1,738	92.4	$\chi^2 = 2.97$
Vision problems limit some activities	73	4.7	21	6.5	94	5.0	$p = .23$
Very limited/legally blind	37	2.4	11	3.4	48	2.6	
Total	1,555		325		1,880	100	
Mobility							
Ambulatory	1,444	92.6	297	91.7	1,741	92.5	$\chi^2 = 0.35$
Nonambulatory	115	7.4	27	8.3	142	7.5	$p = .55$
Total	1,559		324		1,883	100	

Table 1 Continued

Characteristic	HCBS-ICF/MR status						Sig.
	HCBS		ICF/MR		Total		
	<i>n</i>	%	<i>n</i>	%	<i>N</i>	%	
Requires care of nurse or physician							
Less than once/month	1,245	81.2	214	67.1	1,459	78.7	$\chi^2 = 146.93$
At least once/month	215	14.0	47	14.7	262	14.1	$p < .001$
At least once/week	55	3.6	10	3.1	65	3.5	
At least once/day	11	0.7	23	7.2	34	1.8	
24-hr immediate access	8	0.5	25	7.8	33	1.8	
Total	1,534		319		1,853	100	

Note. HCBS = home and community based services; ICF/MR = intermediate care facility; Sig. = significance; ID = intellectual disability; DD = developmental disability.

disabilities. Substantial numbers of individuals with intellectual and developmental disabilities were unable to respond because of communication difficulties and, therefore, were excluded from the current study. As part of the protocol for interviewing individuals with intellectual and developmental disabilities, interviewers were asked to give formal input about the individual's comprehension of the questions and consistency of responses. As a means of ensuring that self-report data being analyzed were as valid and reliable as possible, we selected from among those interviewed who completed Section I and gave codeable responses

to at least half the items. In addition, those who were rated by the interviewer as having "very little understanding or no comprehension" or as "did not give consistent and valid responses" were excluded. More detailed information about instrumentation and sampling is presented in Lakin et al. (2006).

Participants. The selection criteria listed above yielded a total of 1,885 adults with intellectual and developmental disabilities who were recipients of HCBS or ICF/MR services and who had reliable self-report data. This total of sample members able to understand and reliably respond to at least half of the items posed in the subjective Section I

Table 2 Spearman Correlations Among Dependent Variables and Personal Characteristics: HCBS and ICF/MR Recipients in Six States

Demographic/disability-related characteristic	Well-being and satisfaction outcomes							
	Lonely	Afraid at home	Afraid in neighborhood	Happy	Staff nice (home)	Like home	Staff nice (work)	Like work
Age	-.03	-.03	.01	-.03	.06*	.04	.03	.05
Gender	.01	.07**	.06*	.00	.00	-.01	.01	.01
Level of ID	-.01	-.02	.04	.05*	.04	.08***	.02	.05*
Challenging behavior	.07**	.05*	-.01	-.08***	-.05	-.03	-.08**	-.01
Psychiatric diagnosis	.08***	.12***	.09***	-.09***	-.02	-.11***	-.02	-.12***
Seizure or neurological disorder	.06*	.06*	.02	-.04	-.04	-.03	-.03	-.00
Autism diagnosis	.02	.03	.08***	.01	-.00	.06**	.04	.04
Requires care by a nurse or physician	.04	.02	.01	-.12***	-.03	-.09***	-.05	-.05

Note. HCBS = home and community based services; ICF/MR = intermediate care facility; ID = intellectual disability.

* $p < .05$. ** $p < .01$. *** $p < .001$.

Table 3 Living Arrangements for HCBS and ICF/MR Sample Members

Question and response	HCBS–ICF/MR status				Total		χ^2/p
	HCBS		ICF/MR		N	Column %	
	n	Column %	n	Column %			
Persons with disability in residence (5 states)							
1	619	45.3	0	0.0	619	36.9	$\chi^2 = 441.63$ $p < .001$
2–3	467	34.2	20	6.4	487	29.0	
4–6	217	15.9	142	45.5	359	21.4	
7 or more	64	4.7	150	48.1	214	12.7	
Total	1,367	100.0	312	100.0	1,679	100.0	
Residence type (6 states)							
Congregate facility/group home	440	28.4	236	72.6	676	36.0	$\chi^2 = 471.04$ $p < .001$
Agency-operated apartment	181	11.7	89	33.5	270	14.4	
Own home or apartment	366	23.6	0	0.0	366	19.5	
Parent–relative’s home	391	25.2	0	0.0	391	20.9	
Foster care or host home	125	8.1	0	0.0	125	6.7	
Other	47	2.9	3	0.9	50	2.7	
Total	1,550		328		1,878	100	

Note. One state’s data set (Alabama) did not include the number of people with disabilities living in the residential setting. HCBS = home and community based services; ICF/MR = intermediate care facility.

interview made up 64.1% of the entire random sample of HCBS and ICF/MR recipients for whom background information was obtained. Participants’ personal characteristics are summarized in Table 1.

Results

Demographic and Diagnostic Characteristics

Table 1 shows comparisons of HCBS and ICF/MR sample members on demographic and disability-related descriptive information. Chi-square or *t* tests were used to determine if the HCBS and ICF/MR samples differed significantly (final column, Table 1).

Age and Gender

Adult ICF/MR recipients ($M = 45.8$ years) were significantly older than HCBS recipients ($M = 42.5$). The majority (55.7%) were male. There was no significant difference in gender distribution by ICF/MR or HCBS status.

Presence and Level of Intellectual Disability

There were 46 individuals (2.5% of all participants) with developmental disabilities but no intellectual disability label. Compared with the

1,006 participants with mild intellectual disabilities, this group did not differ significantly on any of the eight well-being outcome variables ($ps > .2$ for all variables). Therefore, for all subsequent analyses, we combined these two groups into a single, *mild group* (those without intellectual disabilities made up 4.4% of combined mild group).

Because the study included only participants who gave valid and consistent interview responses, the sample included predominantly people with mild or moderate intellectual disabilities, with only 13.9% of sample members having severe or profound intellectual disabilities. Even so, differences were evident in the HCBS and ICF/MR samples by level of intellectual disability, with a significantly larger proportion of ICF/MR recipients having severe or profound intellectual disabilities.

Other Identified Conditions

Some 35.4% of participants had psychiatric diagnoses, with significantly more ICF/MR sample members so diagnosed. Only 3.6% of participants had autism, with no difference between HCBS (3.3%) and ICF/MR (5.0%) recipients. HCBS (11.7%) and ICF/MR (14.1%) recipients were not statistically different in the reported presence of

cerebral palsy. Seizures or neurological disorders were significantly more prevalent among ICF/MR residents (27.6%) than HCBS recipients (21.3%).

The number of participants with functional vision who were HCBS (92.9%) or ICF/MR (90.2%) recipients was not significantly different. About 2.6% were blind, legally blind, or had very limited vision. There were no significant differences in the percentage of HCBS (92.6%) and ICF/MR (91.7%) recipients reported to be ambulatory. A higher percentage of ICF/MR residents (15.0%) were reported to need medical care from nurses or physicians daily or more often compared with HCBS recipients (1.2%).

Associations With Outcomes

HCBS and ICF/MR participants differed on some demographic (age) and disability-related variables (level of intellectual disability, psychiatric diagnosis, seizure or neurological disorder, requires care of nurse or physician). Spearman rank correlations were calculated to check if these variables were correlated ($p < .001$ because 40 correlations were calculated) with the outcome variables being evaluated. As Table 2 shows, all the correlations were weak, and most were nonsignificant, with only 8 exceeding the .001 criterion. Psychiatric diagnoses were negatively related to well being and satisfaction, as was requiring more medical care, although to a lesser extent. Feeling lonely, afraid at home, or afraid in the neighborhood were all positively related to having a psychiatric diagnosis, whereas self-reported happiness, liking home, and liking work were all negatively related ($p < .001$). Presence of a psychiatric diagnosis was significantly related to six of eight outcomes, with consistently lower satisfaction or well-being in each case.

Liking one's home was related to having a more severe level of intellectual disability, not having a psychiatric diagnosis, and to requiring less frequent medical care. The demographic and disability-related characteristics examined were not significantly related ($p < .001$) to any other outcomes.

Characteristics of Residential Settings

Descriptive information on residential settings is shown in Table 3. HCBS users lived in significantly smaller settings ($p < .001$), with the majority (79.4%) from settings with one to three

residents with disability, whereas almost half (48.1%) of ICF/MR recipients lived in settings of seven or more. Almost half of HCBS respondents (48.8%) lived in their own home or a parent or relative's home, whereas most (72.6%) of ICF/MR recipients lived in large congregate facilities (i.e., institutions) or agency-operated group homes or apartments.

Satisfaction and Well Being by Features of Living Environments

Analyses of well being and satisfaction outcomes by various features of living environments used both univariate (Mann-Whitney or Kruskal-Wallis tests) and multivariate tests (ordinal regression). We used such nonparametric statistics because the dependent variables in our analyses—individual items about satisfaction and well being—each were measured using the 3-point ordinal (rank) scales. Because there were some significant correlations between personal characteristics and these outcomes, where significant univariate differences were found, we used multivariate analysis (ordinal regression) with all eight personal characteristics (level of intellectual disability, challenging behavior, age, gender, autism diagnosis, psychiatric diagnosis, seizures—neurological diagnosis, required care by nurse or physician) as independent variables in addition to the living environment variable of interest.

ICF/MR and HCBS Comparisons

Comparisons between HCBS and ICF/MR recipients (Table 4) showed few significant univariate or multivariate differences.

Loneliness. The HCBS and ICF/MR samples did not differ significantly on loneliness, with 55.1% and 48.4%, respectively, reporting not feeling lonely. Forty-six percent of the entire sample reported feeling lonely sometimes or often, showing that loneliness is a common experience among people with intellectual and developmental disabilities.

Feeling afraid. Almost 80% of interviewees reported not feeling afraid at home and in their neighborhood. There was no significant difference between the HCBS and ICF/MR samples on either issue.

Feeling happy. Around 83% of the sample reported feeling happy, with only 3.7% reporting feeling sad. There was no significant relation with HCBS or ICF/MR status.

Table 4 Outcomes for HCBS and ICF/MR Recipients in Six States

Dependent variable	Independent variable				Analyses	
	HCBS		ICF/MR		Total	Multivariate
	n	Column %	n	Column %		
Question and response						
Do you ever feel lonely?						
Yes – often feels lonely	194	13.2	39	12.6	233	13.1
Sometimes	464	31.7	121	39.0	585	32.9
No – not often	808	55.1	150	48.4	958	53.9
Total	1,466		310		1,776	100
Ever afraid or scared at home?						
Yes – most of the time	74	4.9	17	5.4	91	5.0
Sometimes	228	15.1	49	15.7	277	15.2
No – rarely	1,203	79.9	246	78.8	1,449	79.7
Total	1,505		312		1,817	100
Ever afraid or scared when you are out in your neighborhood?						
Yes – most of the time	109	7.3	25	8.0	134	7.4
Sometimes	195	13.1	45	14.4	240	13.3
No – rarely	1,185	79.6	242	77.6	1,427	79.2
Total	1,489		312		1,801	100
Are you feeling happy or sad ^b today?						
Happy	1,113	83.5	235	81.9	1,348	83.2
In between	168	12.6	44	15.3	212	13.1
Sad	52	3.9	8	2.8	60	3.7
Total	1,333		287		1,620	100
Are staff nice and polite to you?						
Work-daytime activities						
Yes – most staff are nice	1,224	93.6	236	89.1	1,460	92.8
Some staff are nice	73	5.6	19	7.2	92	5.8
No, most staff are not nice	11	0.8	10	3.8	21	1.3
Total	1,308		265		1,573	100

E = .558
p = .017
R² = .039

z = -2.68
p = .007

z = -0.56
p = .58

z = -0.79
p = .43

z = -0.45
p = .65

z = -1.71
p = .09

Table 4 Continued

Dependent variable	Independent variable				Analyses	
	HCBS-ICF/MR status				Mann-Whitney (2-tailed)	Ordinal regression ^a estimate (E) Pseudo-R ^{2c}
	HCBS	ICF/MR	Total			
Question and response	n	Column %	n	Column %	N	Column %
Do you like working (going) there?						
Yes – most of the time	1,234	90.3	244	89.7	1,478	90.2
Sometimes	81	5.9	14	5.1	95	5.8
No	51	3.7	14	5.1	65	4.0
Total	1,366		272		1,638	100
Are staff nice and polite to you?						
Yes	1,055	89.8	290	93.9	1,345	90.6
Sometimes	72	6.1	11	3.6	83	5.6
No	48	4.1	8	2.6	56	3.8
Total	1,175		309		1,484	100
Do you like your home or where you live?						
Yes	1,377	89.3	273	85.0	1,650	88.6
In between	90	5.8	19	5.9	109	5.9
No	75	4.9	29	9.0	104	5.6
Total	1,542		321		1,863	100

Note. HCBS = home and community based services; ICF/MR = intermediate care facility; ID = intellectual disability.

^aOrdinal regression included the following dependent variables: HCBS vs. ICF/MR and eight personal characteristics (level of ID, challenging behavior, age, gender, autism diagnosis, psychiatric diagnosis, seizure/neurological disorder, requires care by nurse or physician). Estimate and probability reported only for “HCBS vs. ICF/MR companions.” ^bParticipants omitted who gave a contradictory answer to a check question about being sad or happy. ^cNagelkerke pseudo-R² for the entire regression equation, including all nine independent variables.

Table 5 Outcomes for Adults With Intellectual and Developmental Disabilities Receiving HCBS and ICF/MR Services in Five States by Size of Residence

Independent variable: Persons with disability in residence	Dependent variable: Question and response								Analyses	
	Do you ever feel lonely?								Univariate	Multivariate
	No – not often		Sometimes		Yes – often feels lonely		Total		Kruskal-Wallis	Ordinal regression ^a estimate (E) Pseudo-R ^{2b}
<i>n</i>	Row %	<i>n</i>	Row %	<i>n</i>	Row %	<i>N</i>	Row %			
1	325	55.4	197	33.6	65	11.1	587	100	$\chi^2 = 15.02$ $df = 3$ $p = .002$	E = .103 $P = .001$ $R_p^2 = .030$
2–3	264	56.2	155	33.0	51	10.9	470	100		
4–6	165	51.7	89	27.9	65	20.4	319	100		
7 or more	89	43.6	78	38.2	37	18.1	204	100		
Total	843		519		218		1,580	100		

Independent variable: Persons with disability in residence	Ever afraid or scared at home?								χ^2
	No – rarely		Sometimes		Yes – most of the time		Total		
	<i>n</i>	Row %	<i>n</i>	Row %	<i>n</i>	Row %	<i>N</i>	Row %	
1	496	82.0	89	14.7	20	3.3	605	100	$\chi^2 = 5.87$ $df = 3$ $p = .12$
2–3	378	79.4	69	14.5	29	6.1	476	100	
4–6	255	76.6	54	16.2	24	7.2	333	100	
7 or more	156	76.5	37	18.1	11	5.4	204	100	
Total	1,285		249		84		1,618	100	

Independent variable: Persons with disability in residence	Ever afraid or scared when you are out in your neighborhood?								χ^2
	No – rarely		Sometimes		Yes – most of the time		Total		
	<i>n</i>	Row %	<i>n</i>	Row %	<i>n</i>	Row %	<i>N</i>	Row %	
1	482	80.7	79	13.2	36	6.0	597	100	$\chi^2 = 2.41$ $df = 3$ $p = .49$
2–3	362	77.2	68	14.5	39	8.3	469	100	
4–6	267	80.2	36	10.8	30	9.0	333	100	
7 or more	161	78.2	30	14.6	15	7.3	206	100	
Total	1,272		213		120		1,605	100	

Independent variable: Persons with disability in residence	Are you feeling happy or sad today? ^c								χ^2
	Sad		In between		Happy		Total		
	<i>n</i>	Row %	<i>n</i>	Row %	<i>n</i>	Row %	<i>N</i>	Row %	
1	17	2.8	82	13.7	499	83.4	598	100	$\chi^2 = 2.36$ $df = 3$ $p = .50$
2–3	15	3.6	56	12.0	393	84.3	466	100	
4–6	18	5.6	45	13.9	261	80.6	261	100	
7 or more	7	3.7	24	12.6	159	83.7	159	100	
Total	59	3.7	207	13.1	1,312	83.1	1,312	100	

This question asked, “Are you feeling happy or sad today?” There was also an oppositely worded, consistency-check question, “Are you feeling sad or happy today?” This allowed us to evaluate the

consistency of responses to this issue. We found that only 32 (1.9%) of 1,652 respondents gave inconsistent (opposite) answers to these questions. We omitted these 32 individuals from the analysis

Table 5 Continued

	Are staff nice and polite to you (at home)?								
	No		Sometimes		Yes		Total		
	<i>n</i>	Row %	<i>n</i>	Row %	<i>n</i>	Row %	<i>N</i>	Row %	
1	22	6.3	15	4.3	312	89.4	349	100	$\chi^2 = 5.02$
2–3	6	1.3	26	5.7	426	93.0	458	100	$df = 3$
4–6	11	3.3	19	5.7	306	91.1	336	100	$p = .17$
7 or more	10	4.8	13	6.3	185	88.9	208	100	
Total	49		73		1,229		1351	100	

	Do you like your home or where you live?									
	No		In between		Yes		Total			
	<i>n</i>	Row %	<i>n</i>	Row %	<i>n</i>	Row %	<i>N</i>	Row %		
1	25	4.0	31	5.0	562	90.9	618	100	$\chi^2 = 15.97$	$E = -.226$
2–3	18	3.7	31	6.4	438	89.9	487	100	$df = 3$	$P = .002$
4–6	24	6.9	28	8.1	294	85.0	346	100	$p = .001$	$R_p^2 = .066$
7 or more	21	10.0	15	7.1	174	82.9	210	100		
Total	88		105		1,468		1,661	100		

Note. HCBS = home and community based services; ICF/MR = intermediate care facility; ID = intellectual disability.

^aOrdinal regression included the following dependent variables: residence size and eight personal characteristics (level of ID, challenging behavior, age, gender, autism diagnosis, psychiatric diagnosis, seizure/neurological disorder, requires care by nurse or physician). Estimate and probability reported only for “residence size companions.” ^bNagelkerke pseudo- R^2 for the entire regression equation, including all nine independent variables. ^cParticipants omitted who gave a contradictory answer to a check question about being sad or happy.

of this question only, and found a Spearman correlation of $r_s = .84$ between the two items, indicating satisfactory consistency.

Work and home staff are nice and polite. For work–day program staff, univariate ($p = .007$) and multivariate ($p = .017$) comparisons showed significantly more HCBS respondents (93.6%) reported that staff were nice than did ICF/MR respondents (89.1%). This situation was reversed for home staff, with significantly more ICF/MR respondents (93.9%) than HCBS respondents (89.8%) reporting that staff were nice. This univariate difference ($p = .030$) was not significant under multivariate analysis ($p = .137$).

Like work–day program. Around 90% of respondents reported liking their job or day program, with no significant difference between the ICF/MR and HCBS samples.

Like home. A small percentage of people did not like their current home (HCBS = 4.9%; ICF/MR = 9.0%), but even this small percentage is of

concern. Significantly more (univariate $p = .022$, multivariate $p = .007$) HCBS sample members (89.3%) reported liking their home than ICF/MR sample members (85.0%).

Overall, there were some differences between HCBS and ICF/MR recipients, but these did not consistently favor either group.

Residence Size

Residence size (the number of people with disabilities per home) is reported in four groups: 1 person, 2–3 persons, 4–6 persons, and 7 or more people. Overall sample size is reduced because residence size was not included in Alabama’s data. Some sample members lived with people without intellectual and developmental disabilities (e.g., HCBS recipients living with family), but residence size reflects only those with intellectual and developmental disabilities. Because living arrangements are not necessarily related to work and day program outcomes, the two items concerning work–

Table 6 Well Being of HCBS Recipients Living With or Away From Family in Six States

Dependent variable question and response	Living with family status				Total N	Column %	Analyses		
	Not with family		With family				Mann-Whitney (2-tailed)	Ordinal regression ^a estimate (E) Pseudo-R ^{2b}	
	n	Column %	n	Column %					
Yes – often feels lonely	164	14.8	30	8.3	194	13.2	$z = -2.67$	$E = .162$	
Sometimes	349	31.6	115	31.9	464	31.7	$p = .008$	$P = .032$	
No – not often	592	53.6	216	59.8	808	55.1		$R_p^2 = .028$	
Total	1,105		361		1,466	100			
Do you ever feel lonely?									
Yes – most of the time	64	5.7	10	2.7	74	4.9	$z = -2.06$	$E = .153$	
Sometimes	176	15.5	52	13.9	228	15.1	$p = .039$	$p = .049$	
No – rarely	892	78.8	311	83.4	1,203	79.9		$R_p^2 = .032$	
Total	1,132		373		1,505	100			
Ever afraid or scared at home?									
Yes – most of the time	89	8.0	20	5.3	109	7.3	$z = -1.23$		
Sometimes	146	13.1	49	13.1	195	13.1	$p = .22$		
No – rarely	880	78.9	305	81.6	1,185	79.6			
Total	1,115		374		1,489	100			
Ever afraid or scared when you are out in your neighborhood?									
Yes – most of the time	89	8.0	20	5.3	109	7.3	$z = -1.23$		
Sometimes	146	13.1	49	13.1	195	13.1	$p = .22$		
No – rarely	880	78.9	305	81.6	1,185	79.6			
Total	1,115		374		1,489	100			
Are you feeling happy or sad today? ^c									
Happy	829	82.0	284	88.2	1,113	83.5	$z = -2.69$	$E = -.167$	
In between	136	13.5	32	9.8	168	12.6	$p = .007$	$p = .395$	
Sad	46	4.5	6	1.9	52	3.9		$R_p^2 = .053$	
Total	1,011		322		1,333	100			
Are staff nice and polite to you (at home)?									
Yes	982	90.8	73	77.7	1,055	89.8	$z = -4.35$	$E = .915$	
Sometimes	68	6.3	4	4.3	72	6.1	$p < .001$	$p = .001$	
No	31	2.9	17	18.1	48	4.1		$R_p^2 = .035$	
Total	1,081		94		1,175	100			
Do you like your home or where you live?									
Yes	1,005	87.2	372	95.6	1,377	89.3	$z = -4.74$	$E = -.961$	
In between	77	6.7	13	3.3	90	5.8	$p < .001$	$p < .001$	
No	71	6.2	4	1.0	75	4.5		$R_p^2 = .070$	
Total	1,153		389		1,542	100			

Note. HCBS = home and community based services; ID = intellectual disability.

^aOrdinal regression included the following dependent variables: lives with family or not and eight personal characteristics (level of ID, challenging behavior, age, gender, autism diagnosis, psychiatric diagnosis, seizure/neurological disorder, requires care by nurse or physician). Estimate and probability reported only for “lives with family or not.”

^bNagelkerke pseudo-R² (R_p²) for the entire regression equation, including all nine independent variables.

^cParticipants omitted who gave a contradictory answer to a check question about being sad or happy.

day program were not examined for any subsequent analyses. Table 5 shows the results for the remaining six satisfaction and well-being items by residence size.

Where significant univariate differences (Kruskal-Wallis test) were found, we used ordinal regression with the eight personal characteristics mentioned previously as independent variables, in addition to residence size, to control for possible differences in personal characteristics by residence size.

Loneliness. Individuals from larger settings reported significantly more loneliness under both univariate ($p = .002$) and multivariate ($p = .001$) analyses. If we omit the 7+ group, differences in loneliness by residence size are no longer significant, $\chi^2(2, N = 754) = 5.54, p = .063$, suggesting that the effect is largely due to more people in settings with 7+ residents being lonely.

Feeling afraid, feeling happy, and home staff are nice and polite. There was no significant difference by residence size for any of the following variables: feeling afraid at home or in the neighborhood, feeling happy, and home staff are nice and polite.

Like home. Significantly more residents of smaller settings reported liking where they live under both univariate ($p = .001$) and multivariate ($p = .002$) analyses.

Overall, most outcome variables were not significantly related to residence size. Loneliness and liking home both showed consistently worse outcomes for larger settings.

Living With Family

Of HCBS recipients, 25.1% lived in the parents' or relative's home, whereas ICF/MR services are only available in congregate settings. ICF/MR recipients were omitted from these analyses to avoid attributing differences to family and nonfamily residence that may have been due to ICF/MR status. In comparing HCBS recipients living with family members with those in other living arrangements (Table 6), if significant univariate differences were found, ordinal regression was used to control for personal characteristics.

Loneliness. Univariate ($p = .008$) and multivariate ($p = .032$) analyses showed that individuals living with family were significantly less lonely, with 8.3% reporting often feeling lonely versus 14.8% from nonfamily settings.

Feeling afraid. There was no significant univariate difference in feeling afraid in one's neighborhood between those living with family or not. Univariate ($p = .039$) and multivariate ($p = .049$) analyses revealed that family dwellers (2.7% scared most of the time) were significantly less afraid at home than those living elsewhere (5.7%).

Feeling happy. Self-reported happiness was significantly higher among those living at home under univariate analysis ($p = .007$) but not multivariate analysis ($p = .053$). Some 88.1% of those living with family said they felt happy versus 81.0% of those living elsewhere.

Home staff are nice and polite. Fewer participants who lived with their family and had home support reported that home support staff were nice and polite (77.7%) compared with respondents from nonfamily living arrangements (90.8%). This difference was significant under both univariate ($p < .001$) and multivariate analyses ($p = .001$).

Like home. Living with family was significantly related to liking where one lives under univariate ($p < .001$) and multivariate ($p < .001$) analyses, with 95.6% of individuals living with family liking home versus 87.2% from nonfamily HCBS settings.

Choice of With Whom and Where to Live

Participants responded to questions about whether they chose with whom they lived and where they lived. Responses were coded on a 3-point scale (0 = no choice, 1 = some choice, 2 = full choice). Choice of living companions and where to live were significantly positively correlated ($r_s = .42, p < .001$) but far from identical. These are related but distinct issues, so we analyzed the satisfaction and well-being data separately for groups defined by their degree of choice about where and with whom to live. These questions were not asked of participants who lived with family, so the following analyses exclude those living with family.

Choice of Living Companions

As with previous analyses, if significant univariate differences (Kruskal-Wallis test) were found, we used multivariate analysis (ordinal regression) with eight personal characteristics as independent variables, in addition to choice of living companions, to control for possible differences in personal characteristics. The results for choice of living companions are reported in Table 7.

Table 7 Well Being of HCBS and ICF/MR Recipients Not Living With Family by Choice of Living Companions in Six States

Dependent variable question and response	Choice of living companion status						Analyses		
	No choice		Some choice		Full choice		Total	Univariate Kruskal-Wallis (df = 2)	Multivariate Ordinal regression ^a estimate (E) pseudo-R ^{2b}
	n	Column %	n	Column %	n	Column %			
Do you ever feel lonely?									
Yes – often feels lonely	103	18.1	42	13.9	46	10.4	191	14.5	$\chi^2 = 9.09$ $p = .011$ $R_p^2 = .032$ $E = -.102$ $p = .008$
Sometimes	191	33.6	96	31.8	153	34.5	440	33.5	
No – not often	275	48.3	164	54.3	245	55.2	684	52.0	
Total	569		302		444		1,315		
Ever afraid or scared at home?									
Yes – most of the time	35	6.0	18	5.9	17	3.8	70	5.2	$\chi^2 = 0.23$ $p = .89$
Sometimes	81	14.0	48	15.6	77	17.1	206	15.4	
No – rarely	464	80.0	241	78.5	356	79.1	1,061	79.4	
Total	580		307		450		1,337		
Ever afraid or scared when out in your neighborhood?									
Yes – most of the time	41	7.5	30	9.9	30	6.8	101	7.6	$\chi^2 = 0.37$ $p = .83$
Sometimes	75	13.0	34	11.3	65	14.7	174	13.2	
No – rarely	471	79.9	238	78.8	348	78.6	1,047	79.2	
Total	577		302		443		1,322		
Are you feeling happy or sad today? ^c									
Happy	380	78.2	255	86.4	358	83.6	993	82.1	$\chi^2 = 9.58$ $p = .008$ $R_p^2 = .041$ $E = .190$ $p = .020$
In between	81	16.7	30	10.2	57	13.3	168	13.9	
Sad	25	5.1	10	3.4	13	3.0	48	4.0	
Total	486		295		428		1,209		
Are staff nice and polite to you (at home)?									
Yes	522	88.9	291	93.3	385	93.7	1,198	91.5	$\chi^2 = 8.59$ $p = .014$ $R_p^2 = .064$ $E = .387$ $p = .002$
Sometimes	46	7.8	17	5.4	15	3.6	78	6.0	
No	19	3.2	4	1.3	11	2.7	34	2.6	

Table 7 Continued

Dependent variable question and response	Choice of living companion status						Analyses		
	No choice		Some choice		Full choice		Total	Univariate	Multivariate
	<i>n</i>	Column %	<i>n</i>	Column %	<i>n</i>	Column %	<i>N</i>	Kruskal-Wallis (<i>df</i> = 2)	Ordinal regression ^a estimate (E) pseudo- <i>R</i> ^{2b}
Total	587		312		411		1,310		
Yes	482	81.4	300	93.8	397	87.6	1,179	$\chi^2 = 28.17$	E = .291
In between	50	8.4	10	3.1	31	6.8	91	<i>p</i> < .001	<i>p</i> = .002
No	60	10.1	10	3.1	25	5.5	95		<i>R</i> _p ² = .069
Total	592		320		453		1,365		

Note. HCBS = home and community based services; ICF/MR = intermediate care facility; Sig. = significance; ID = intellectual disability.

^aOrdinal regression included the following dependent variables: choice of living companions and eight personal characteristics (level of ID, challenging behavior, age, gender, autism diagnosis, psychiatric diagnosis, seizure/neurological disorder, requires care by nurse or physician). Estimate and probability reported only for choice of living companions. ^bNagelkerke pseudo-*R*² for the entire regression equation, including all nine independent variables.

Table 8 Well Being of HCBS and ICF/MR Recipients Not Living With Family by Choice of Where One Lives in Six States

Dependent variable question and response	Choice where one lives status						Total		Analyses	
	No choice		Some choice		Full choice		N	Column %	Univariate Kruskal-Wallis (df = 2)	Multivariate Ordinal Regression ^a estimate (E) pseudo-R ^{2b}
	n	Column %	n	Column %	n	Column %				
Do you ever feel lonely? ^c										
Yes – often feels lonely	88	20.9	73	11.3	37	14.1	198	14.9	$\chi^2 = 1.76$	E = -.084 p = .074 R _p ² = .032
Sometimes	115	27.3	248	38.3	84	31.9	447	33.6	p = .42	
No – not often	219	51.9	326	50.4	142	54.0	687	51.6		
Total	422		647		263		1,332			
Ever afraid or scared at home? ^c										
Yes – most of the time	35	8.2	29	4.4	12	4.5	76	5.6	$\chi^2 = 6.54$	E = -.084 p = .074 R _p ² = .032
Sometimes	71	16.7	96	14.5	43	16.3	210	15.6	p = .038	
No – rarely	319	75.1	536	81.1	209	79.2	1,064	78.8		
Total	425		661		264		1,350			
Ever afraid or scared when you are out in your neighborhood? ^c										
Yes – most of the time	42	10.1	47	7.2	16	6.1	105	7.9	$\chi^2 = 1.15$	E = -.084 p = .074 R _p ² = .032
Sometimes	51	12.3	89	13.6	36	13.6	176	13.2	p = .56	
No – rarely	323	77.6	517	79.2	212	80.3	1,052	78.9		
Total	416		653		264		1,333			
Are you feeling happy or sad today? ^c										
Happy	244	74.6	511	85.5	204	82.3	959	81.8	$\chi^2 = 17.39$	E = .295 p = .005 R _p ² = .048
In between	61	18.7	70	11.7	35	14.1	166	14.2	p < .001	
Sad	22	6.7	17	2.8	9	3.6	48	4.1		
Total	327		598		248		1,173			
Are staff nice and polite to you (at home)? ^c										
Yes	376	87.6	596	93.0	226	93.4	1,198	91.3	$\chi^2 = 10.15$	E = .473 p = .001 R _p ² = .064
Sometimes	42	9.8	25	3.9	11	4.5	78	5.9	p = .006	
No	11	2.6	20	3.1	5	2.1	36	2.7		
Total	429		641		242		1,312			
Do you like your home or where you live? ^c										
Yes	351	80.1	599	89.1	241	89.6	1,199	86.4	$\chi^2 = 22.88$	E = .482 p < .001 R _p ² = .074
In between	34	7.8	45	6.7	13	4.8	92	6.7	p < .001	
No	53	12.1	28	4.2	15	5.6	96	7.0		
Total	438		672		269		1,379			

Note. HCBS = home and community based services; ICF/MR = intermediate care facility; Sig. = significance; ID = intellectual disability.
^aOrdinal regression included the following dependent variables: choice of living companions and eight personal characteristics (level of ID, challenging behavior, age, gender, autism diagnosis, psychiatric diagnosis, seizure/neurological disorder, requires care by nurse or physician). Estimate and probability reported only for “choice of living companions.”
^bNagelkerke pseudo-R² for the entire regression equation, including all nine independent variables.
^cParticipants omitted who gave a contradictory answer to a check question about being sad or happy.

Loneliness. There were significant univariate ($p = .011$) and multivariate ($p = .008$) differences in loneliness by degree of choice of living companions. Those with less choice reported more loneliness: 18.1% of those with no choice of living companions reported often feeling lonely versus 13.9% with some choice and 10.4% with full choice.

Feeling afraid. No significant univariate difference by choice of living companions was evident concerning feeling afraid at home or in one's neighborhood.

Feeling happy. For univariate ($p = .008$) and multivariate ($p = .020$) analyses, reported happiness was significantly lower among those with no choice of living companions (78.2% reported feeling happy) compared with those with some choice (86.4%) and with full choice (83.6%).

Home staff are nice and polite. Responses about home support staff differed significantly (univariate $p = .014$, multivariate $p = .002$) by choice of living companions, with 88.9% of those with no choice of living companions reporting that home support staff were nice and polite compared with 93.3% with some choice and 93.7% with full choice.

Like home. Univariate ($p < .001$) and multivariate ($p = .002$) analyses showed that choice of living companions was significantly related to liking where one lives, with 81.4% of individuals with no choice liking their living situation versus 93.8% with some choice and 87.6% with full choice.

Overall, the univariate and multivariate results showed a clear and consistent pattern, with those who had no choice of living companions being significantly more likely to feel lonely, unhappy, to dislike their home, and to have staff they did not consider nice. Values of pseudo- R^2 were all less than .10, showing that choice of living companions accounted for a small to medium amount of the variance in these satisfaction and well-being outcomes.

Choosing Where One Lives

Similar analyses to those just described were undertaken using "choosing where one lives" as the independent variable.

Loneliness. There was no significant univariate difference in loneliness by choice of where one lives.

Feeling afraid at home. A significant univariate difference was evident concerning feeling afraid at

home by choice of where one lives ($p = .038$), with more of those with no choice reporting feeling afraid, but this association was not significant under multivariate analysis ($p = .074$).

Feeling afraid in one's neighborhood. No significant univariate difference was evident concerning feeling afraid in one's neighborhood by choice of where one lived.

Feeling happy. For both univariate ($p < .001$) and multivariate ($p = .005$) analyses, reported happiness was significantly lower among those with no choice of where one lives (74.6% reported feeling happy) compared with those with some choice (85.5%) and with full choice (82.3%).

Home staff are nice and polite. Responses about home support staff differed significantly by choice of where one lives, for both univariate ($p = .006$) and multivariate ($p = .001$) analyses, with 87.6% of those with no choice reporting that staff were nice and polite compared with 93.0% with some choice and 93.4% with full choice.

Like home. Univariate ($p < .001$) and multivariate ($p < .001$) analyses both showed that choice of where one lives was significantly related to liking where one lives, with 80.1% of individuals with no choice liking their living situation versus 89.1% with some choice and 89.6% with full choice.

Overall, the univariate results showed that those with no choice of where to live were significantly more likely to feel afraid at home, unhappy, to have staff they did not consider nice, and to dislike their home. Multivariate analyses controlling for personal characteristics confirmed these univariate findings except for feeling afraid at home. The values of pseudo- R^2 (all less than .08) showed that choice of where one lives accounted for a small to medium amount of the variance in satisfaction and well-being outcomes.

Discussion

Participants were included in this study if they were judged by interviewers to have given valid and consistent self-report responses. Consequently, the sample consisted mostly of people with mild or moderate intellectual disabilities. Comparisons of personal characteristics by HCBS and ICF/MR status showed that the ICF/MR sample was older, had more severe disability, was diagnosed with a psychiatric diagnosis and seizures–neurological disorder more often, and reportedly required more

frequent medical care than those receiving HCBS. As expected, more ICF/MR service users lived in larger congregate settings. Living in a parent's or relative's home was exclusive to HCBS users. Residence size and living with family were specifically investigated in subsequent comparisons. These differences in personal characteristics and living arrangements need to be considered when interpreting our findings. Where univariate differences were found, multivariate analyses (ordinal regression) were also conducted to control for differences in personal characteristics. One consistent relation between personal characteristics and satisfaction–sense of well being involved psychiatric diagnoses. Consistently lower satisfaction or well being accompanied a psychiatric diagnosis.

There were few differences by HCBS and ICF/MR status (Table 4), with no consistent pattern favoring either sample. In part, this may reflect the fact that some HCBS congregate services (e.g., group homes) are, like ICFs/MR, neither individualized nor flexible. Significantly more HCBS users reported that work–day program staff were nice and polite, whereas the opposite was true regarding staff at home, with ICF/MR users reporting more favorably. Loneliness was the most widespread problem, and there were also small percentages of people who reported negative views in the other areas evaluated.

The high level of well being and satisfaction reported for most indicators is consistent with the notion that average satisfaction will be about 75% of the scale maximum (Cummins, 2001) and may be reflective of individual temperament or lack of awareness of alternatives and not simply the quality of services. Loneliness was notable for its markedly lower levels of well being. This suggests that loneliness requires sustained attention by service providers, policymakers, and researchers. We have examined the loneliness data in considerably more detail in a companion paper (Stancliffe et al., 2007).

Comparisons by residence size yielded a more consistent picture (Table 5), with more negative findings always associated with larger residence size. Residents of larger settings were significantly more lonely, with the main difference being due to greater loneliness in settings with seven or more residents, where the majority reported feeling lonely sometimes or often. Service users from smaller settings liked their home significantly more. Given that measures of satisfaction and well being rarely relate to objective features of the environ-

ment (Cummins, 2001; Perry & Felce, 2005), the consistent findings favoring smaller living settings are notable and provide additional evidence to support the initiatives to increase opportunities for persons with intellectual and developmental disabilities to live in smaller community homes.

Comparisons among HCBS users who lived with parents–relatives or elsewhere presented an even more consistent picture. Under both univariate and multivariate analyses, loneliness, being afraid at home, and liking where you live yielded significantly more positive results for those living with family. Feeling happy significantly favored those living with family for univariate analysis only. These findings strongly endorse the growing trend to fund family-based services to support people with intellectual and developmental disabilities to remain living with their family.

Those living with family reported one negative result. Individuals who received in-home support from paid workers reported that staff were less nice and polite compared with those who lived elsewhere. It is not clear why this was the case. One possibility is that, compared with family members who are constant in the person's life, individuals with intellectual and developmental disabilities living with family may feel less comfortable with paid staff who come and go daily and change over time. Conversely, those who did not live with family may particularly appreciate the human contact provided by support staff.

Comparisons by choice of living companions yielded consistent results favoring those who chose with whom they live. For both univariate and multivariate analyses, four of six outcomes were more positive with greater choice of living companions: loneliness, feeling happy, staff are nice, and liking home (Table 7). Likewise, those with greater choice of where to live had more positive outcomes for feeling scared at home, feeling happy, staff are nice (univariate and multivariate comparisons significant), and liking home (only univariate significant).

Among the six indicators of well being and satisfaction examined in all the analyses, some items were more sensitive to differences in living arrangements than others. Liking one's home more was significant in all analyses and was associated with HCBS, smaller settings, living with family, choosing living companions, and choosing where one lives. Even though very high levels of liking home were reported (>86% said they liked where

they live), this item does distinguish between different living arrangements in useful ways, with medium-sized differences evident between living arrangements (values of R^2 ranged from .060 to .074). The item about loneliness is also an important indicator because substantial numbers reported being lonely. In addition, less loneliness was significantly associated with smaller settings, living with family, and choosing living companions.

Other items were less consistently associated with differences in living arrangements under both univariate and multivariate analyses. Feeling happy was associated with both choice of where and with whom to live. Feeling less scared at home was associated with living with family. Perceiving home staff to be nice had seemingly contradictory findings in that there were positive associations with choosing both where and with whom to live, but those living with family reported more negative outcomes. Feeling scared in one's neighborhood was not significantly associated with living arrangements in any of our analyses.

Limitations

This study has several limitations. First, although no interviewers were directly responsible for coordinating participants' services, state quality assurance staff conducted interviews in some states. Interviews conducted by staff involved with the service system may have affected respondents' willingness to express their true feelings. However, quality assurance staff were far removed from day-to-day service provision and were likely to be perceived as independent by most interviewees. Second, there are limitations to the extent to which survey research can truly tap subjective, personal views. In-depth interviews likely would have been more effective in exploring such issues in detail and in uncovering the reasons behind the well-being findings. Third, each of the well-being items only provided three response alternatives. Such a restricted range in our dependent variables limited variability and, therefore, reduced the magnitude of the association with other variables examined. An implication of this constraint is that the effects we found may well represent conservative estimates of the true magnitude of these effects. Last, although our sample was relatively large and made up of random samples of service users from a number of states across the country, it was not a national sample, so broader generalization requires some caution.

Conclusion

Overall, the self-reported well-being and satisfaction findings examined here document the benefits of residential support provided in very small settings, with choice of where and with whom to live and to individuals living with family. Careful attention needs to be given to reducing loneliness. People with a psychiatric diagnosis may be particularly vulnerable to poorer satisfaction and sense of well being. Among the indicators examined, items about liking where you live and loneliness proved to be the most useful in distinguishing between various living arrangements.

References

- Anderson, L., Polister, B., Prouty, R., & Lakin, K. C. (1999). Number of residential settings and residents by type of living arrangements. In R. Prouty & K. C. Lakin (Eds.), *Residential services for persons with developmental disabilities: Status and trends through 1998* (pp. 79–83). Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Burchard, S. N., Hasazi, J. E., Gordon, L. R., & Yoe, J. (1991). An examination of lifestyle and adjustment in three community residential alternatives. *Research in Developmental Disabilities, 12*, 127–142.
- Coucovanis, K., Prouty, R. W., & Lakin, K. C. (2006a). Number of residential settings and residents by type of living arrangement on June 30, 2005. In R. W. Prouty, G. Smith, & K. C. Lakin (Eds.), *Residential services for persons with developmental disabilities: Status and trends through 2005* (pp. 45–49). Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Coucovanis, K., Prouty, R. W., & Lakin, K. C. (2006b). Services provided by state and non-state agencies in 2005. In R. W. Prouty, G. Smith, & K. C. Lakin (Eds.), *Residential services for persons with developmental disabilities: Status and trends through 2005* (pp. 36–43). Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Cummins, R. A. (2001). Living with support in the community: Predictors of satisfaction with life. *Mental Retardation and Developmental Disabilities Research Reviews, 7*, 99–104.

- Cummins, R. A. (2002). Proxy responding for subjective well-being: A review. *International Review of Research in Mental Retardation*, 25, 183–207.
- Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., et al. (2001). (2001). Quality and costs of supported living residences and group homes in the United Kingdom. *American Journal on Mental Retardation*, 106, 401–415.
- Gardner, J. F., & Carran, D. T. (2005). Attainment of personal outcomes by people with developmental disabilities. *Mental Retardation*, 43, 157–174.
- Howe, J., Horner, R. H., & Newton, J. S. (1998). Comparison of supported living and traditional residential services in the state of Oregon. *Mental Retardation*, 36, 1–11.
- Krauss, M. W., Seltzer, M. M., & Jacobson, H. T. (2005). Adults with autism living at home or in non-family settings: positive and negative aspects of residential status. *Journal of Intellectual Disability Research*, 49, 111–124.
- Lakin, K. C., Doljanac, R., Byun, S., Stancliffe, R. J., Taub, S., & Chiri, G. (2006). *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*. Minneapolis: University of Minnesota, Research and Training Center on Community Living.
- Lakin, K. C., Doljanac, R., Byun, S., Stancliffe, R. J., Taub, S., & Chiri, G. (2008). Choice making among Medicaid Home and Community-Based Services (HCBS) and ICF/MR recipients in six states. *American Journal on Mental Retardation*, 113, 325–342.
- National Association of State Directors of Developmental Disability Services (NASDDDS) & Human Services Research Institute (HSRI). (2002). *Core indicators project: Consumer survey*. Cambridge, MA: Author.
- Perry, J., & Felce, D. (2005). Correlation between subjective and objective measures of outcome in staffed community housing. *Journal of Intellectual Disability Research*, 49, 278–287.
- Prouty, R., & Lakin, K. C. (1995). *Residential services for persons with developmental disabilities: Status and trends through 1994*. Minneapolis: University of Minnesota, Research and Training Center on Community living.
- Prouty, R., Smith, G., & Lakin, K. C. (2006). *Residential services for persons with developmental disabilities: Status and trends through 2005*. Minneapolis: University of Minnesota, Research and Training Center on Community Living. Accessed July 2006. Available at <http://rtc.umn.edu/docs/RISP2004>
- Smith, G., & Ashbaugh, J. (2001). National Core Indicators Project: Phase II consumer survey technical report. Cambridge, MA: Human Services Research Institute. Accessed July 2006. Available at <http://www.hsri.org>
- Stancliffe, R. J., Lakin, K. C., Taub, S., Doljanac, R., Byun, S., & Chiri, G. (2007). Loneliness and living arrangements. *Intellectual and Developmental Disabilities*, 45, 380–390.

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