

Community participation and staying home if you want: US adults with intellectual and developmental disabilities

Roger J. Stancliffe  | Sandra L. Pettingell  | Julie Bershadsky |
James Houseworth  | Renáta Tichá

Institute on Community Integration, University of Minnesota, Minneapolis, USA

Correspondence

Roger J. Stancliffe, Institute on Community Integration, University of Minnesota, 2025 East River Parkway (MIDB 1-324), Minneapolis, MN 55414, USA.
Email: stan0185@umn.edu

Funding information

National Institute on Disability Independent Living and Rehabilitation Research, U.S. Department of Health and Human Services, Grant/Award Number: #90RTCP0003

Abstract

Background: Requiring adults with intellectual and developmental disabilities to go on community outings with co-residents and staff is contrary to community-living policy's focus on person centredness and choice of activities/companions.

Method: We analysed 2018-19 National Core Indicators data from 36 US states concerning 7968 adults living in staffed, non-family, multi-client settings. The focus outcome was being able to stay home if you want when others in your home go out.

Results: The 42.0% of participants who could stay home were more likely to go out with friends, family or alone, and less likely to go out with staff. Those who could stay home participated in a similar variety of community activities and went out more often to shop or for errands.

Conclusions: Individuals who could stay home likely had more choice about where, when and with whom they went out. Strategies for greater person-centredness are proposed.

KEYWORDS

block treatment, community participation, disabilities, intellectual and developmental, living arrangements, staying home alone

1 | INTRODUCTION

Many United States adults with intellectual and developmental disabilities reside in staff-supported living settings, the vast majority (93.6%) being community based and financed through Medicaid Home and Community-Based Services (HCBS) funding (Larson et al., 2020). Community living is expected to provide greater person-centredness, community participation, and choice, and be free of the regimentation of institutions. However, institutional practices persist in some staffed community-living settings, such as group homes (Bigby, Cooper, & Reid, 2012; Bigby, Knox, et al., 2012). Kozma et al.'s (2009) review of deinstitutionalisation research concluded that most community-living

residents are better off than institution dwellers, but there is considerable variability in outcomes among community-living settings, with staff support practices being an important influence on outcomes.

Block treatment is one cardinal feature of institutions (Pratt et al., 1980). It is the opposite of person centeredness, with individual residents being treated as a group, regardless of personal preference or need. An example is all group home residents being required to attend a community outing together irrespective of each person's interest in the activity or preferences for companions. Bigby, Knox, et al. (2012) examined staff working practices in Australian group homes that had poorer resident outcomes, such as community participation. They found group treatment to be a key dimension of

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial-NoDerivs](https://creativecommons.org/licenses/by-nc-nd/4.0/) License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2022 The Authors. *Journal of Applied Research in Intellectual Disabilities* published by John Wiley & Sons Ltd.

detrimental institution-like, staff-centred working practices and reported that 'group treatment was particularly integral to activities that occurred outside the house' (p. 460). Bigby, Cooper, and Reid (2012) assessed levels of block treatment of Australian group-home residents who had moved from an institution 1 year previously and found these block-treatment scores still averaged 69% of institutional levels. Staff and/or residents may bring institutional practices with them when transitioning from institutional to community-living settings. However, with many US community residents and staff having no history of institutionalisation, the extent of block treatment in current US community-living settings is unclear.

Block treatment is incompatible with current US community-living policy such as the HCBS Final Settings Rule, a landmark federal regulation issued in 2014 by the Centers for Medicare and Medicaid Services (CMS). This rule has an emphasis on 'independence in making life choices, including ... daily activities, physical environment, and with who to interact' (Riesen & Snyder, 2019, p. 15). As a condition of future continued HCBS funding, all US states are required to have transition plans approved by CMS by March 2023 (Friedman, 2020). These plans set out the process of transition to meeting the requirements of the Final Rule.

The assumed specific benefits of being able to stay home if the individual wishes to are that the person is not required to go out to non-preferred activities or with non-preferred companions, and instead has greater choice about which community activities to participate in and more options about companions to do the chosen activity with. However, we found no research that evaluated these assumptions empirically.

Being able to stay home should not affect how often the person goes out into the community, but instead give the individual more control over when, where and with whom they do go out. However, it is currently unknown to what extent this ideal is realised. One possible consequence of staying home that we examine in the current study is whether individuals who can do so participate in community activities less often and/or take part in fewer different types of activities. It is well established that people with intellectual and developmental disabilities engage in few community activities and less than general population (Verdonschot et al., 2009), so any potential to further limit such activities should be examined carefully.

The National Core Indicators In-Person Survey (NCI-IPS) is the only annual survey of US adult intellectual and developmental disability service users that focusses on community-living services (NCI, 2019b). Its multi-state sample and large scale provide ample statistical power to enable multiple subgroup comparisons of outcomes of interest while controlling for key variables. The current study uses 2018-19 NCI-IPS data that were collected before the COVID-19 pandemic and were unaffected by it.

Institutional-style block treatment occurs in disability service settings with two or more residents because, by definition, a person who lives alone cannot go out with co-residents. This reality is recognised in the NCI-IPS which instructs interviewers to not ask the question about staying home of people who live alone. In addition, block treatment is conceptualised as a disability staff-driven practice which

therefore requires staff to be present in the person's home at least part of the time. Consequently, we restricted our analyses to staffed, non-family, multi-client residential settings.

We investigated the following three research questions:

1. What is the prevalence of being able to stay home by current living arrangements and current staffing level?
2. Is being able to stay home related to whom you go out with?
3. Do people who can stay home participate less often in community activities or take part in fewer different types of community activity?

2 | METHOD

The University of Minnesota's institutional review board (IRB) reviewed this research and granted a waiver of ongoing IRB review and approval because it involved secondary analysis of deidentified data.

2.1 | Sample

2.1.1 | Participating states

For 2018–2019, the NCI-IPS data we analysed were collected from 36 US states: Alabama, Arkansas, Arizona, Colorado, Connecticut, Delaware, Florida, Georgia, Hawaii, Indiana, Kansas, Kentucky, Maine, Michigan, Missouri, North Carolina, Nebraska, New Hampshire, New Jersey, Nevada, New York, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Carolina, South Dakota, Tennessee, Texas, Utah, Virginia, Vermont, Washington, Wisconsin, and Wyoming (NCI, 2019a). Minnesota participated in the 2018–2019, NCI-IPS survey, but provided no data on the amount of staff support at home. The NCI-IPS is organised by the National Association of State Directors of Developmental Disabilities Services and the Human Services Research Institute and is a component of a national project focused on quality assurance (NCI, 2019b).

Within state sample selection

Each year, each participating state is asked to recruit 400 or more participants, randomly selected from their population of adults with intellectual and developmental disabilities, aged 18 years or older, who received at least one funded disability support service in addition to case management. Some states had additional restrictions for their samples (e.g., recipients of HCBS services only). Each state's sampling strategy can be found in Appendix B in NCI's 2018–2019 IPS Final Report (NCI, 2019a).

2.2 | Participants

We restricted our analyses to participants with non-missing data on being able to stay home who lived in non-family, multi-client settings. This meant that those who lived alone, with family, in a foster/host

home or in 'other' (homeless, emergency, unspecified) residential settings were excluded from all analyses. These selection criteria yielded a sample of $N = 9598$.

In addition, we only included participants with clear evidence that they received at least some paid staff support at home. This criterion reduced the sample to 7968, with 1414 (1217 from Minnesota) potential participants excluded due to missing data on amount of staff support at home, and the remaining 216 (2.3%) excluded because the staffing level was unclear.

Among participants who were eligible based on living arrangements and availability of staffing data, missing data (e.g., do not know, no response) for the staying home item affected 431 individuals, with missing data rates by living arrangement ranging from 4.2% (group 4–6) to 7.3% (group 7–15).

The analysed sample consisted of 7968 adults with intellectual and developmental disabilities. Analysed samples per state ranged from 51 (Hawaii) to 1169 (Texas) with an average of 221. Average age was 48.12 years ($SD = 15.34$, range 18–98). There were 4642 (58.3%) men, 3297 (41.4%) women, 5 (0.1%) with other gender, and 24 (0.3%) with gender missing. Overall, 5873 (73.7%) participants were white, 1296 (16.3%) black, 376 (4.7%) Hispanic, 291 (3.7%) other racial/ethnic groups, and 132 (1.7%) had missing race/ethnicity data.

2.3 | Instrument

Data from two sections of the NCI-IPS 2018–2019 were used. Data on participant personal characteristics, level of intellectual disability, amount of paid support at home, and living arrangements were collected in the Background Information Section. This information usually comes from case management and service provider records. Data from NCI-IPS Section II included questions about frequency of and companions for various community activities and being able to stay home if you want. Respondents to Section II were the persons receiving services where possible or, if the person is unwilling or unable, family, an advocate, or staff. Survey interviewers participated in an NCI programme to guarantee consistency in training, understanding of the survey, and familiarity with data collection procedures (NCI, 2019b).

2.3.1 | Variables

Living arrangements

This NCI-IPS item had 14 mutually-exclusive response options for living-arrangement type, which we recoded into eight categories, five of which were used in the current study: (a) Own home (may be owned, rented, or shared with spouse or roommates) with some disability staff support, and the following settings each operated by a service provider agency (b) Group 2–3, (c) Group 4–6, (d) Group 7–15 (group living settings for the specified number of people with disabilities, including intermediate care facility [ICF], HCBS and other types of funding), and (e) Institution (ICF-funded setting with 16+ residents with disabilities, nursing facility, ICF other specialised institutional facility).

Amount of paid support at home

This item's mutually-exclusive response options were: (a) 24-h support/supervision (i.e., whenever person is at home), (b) daily (limited hours, not round-the-clock), (c) scheduled but less than daily, and (d) as needed. For analysis, these categories were recoded into a binary variable of 24-h support (yes/no). A fifth category 'None of the above' was considered too difficult to interpret, so 216 participants with this response were excluded from all analyses, as noted.

Level of intellectual disability

This single item, ranging from mild to profound intellectual disability, was treated as a quasi-continuous variable ranging from 1 (mild) to 4 (profound). Analyses including this variable only involve participants with intellectual disability, and those with an unspecified level, unknown, or no intellectual disability were excluded.

Companions for community activity

Participants could indicate (yes/no) whether they did the activity alone, with friends, family, housemates, or staff. They could select all categories of companions that applied. The companions question was asked separately for each of the five community-activity types (going out for entertainment, eating out, shopping, errands, and attending a religious service).

Frequency of community activity

For each of the five community-activity types, respondents were asked to select how frequently they participated in the past month (0, 1–2, 3–4, or 5+).

Variety of community activities

For each of five types of community activities, zero frequency was coded *no*, and non-zero frequencies were coded *yes*. The number of different community activities was a count of the *yes* responses and could range from 0 to 5. This total was computed with listwise deletion of cases with missing data.

Staying home

The single staying-home item '(If not currently living alone) when people in your house go somewhere, do you have to go too, or can you stay at home if you want to?' had three response options: Yes, can stay at home; Sometimes can stay at home but sometimes has to go; and No, always has to go.

2.4 | Data analysis

Analyses were primarily descriptive, with data grouped by living arrangement for several analyses. Depending on level of measurement and whether other assumptions were met, differences in (a) being able to stay home, and (b) frequency (high vs. low) of community activity were analysed using chi square, Fishers exact test, or logistic regression. Because the relevant data failed Levene's homogeneity of variance test, for continuous data (counts of different types of community activities with each type of companion and overall), we used mixed linear modelling

with level of intellectual disability as a covariate. This analytic approach uses maximum likelihood estimation which produces asymptotically efficient estimators for unbalanced and balanced designs, allows the flexibility of selecting the appropriate covariance structure, and can handle correlated data and unequal variances (SPSS Inc 2005; Weaver & Black, 2015). In total, we report 17 separate primary analyses. To correct for the number of analyses and account for Type 1 error, we have adjusted alpha to be .05/17, with significance reported at $p < .0029$. All analyses were conducted using SPSS version 27 (IBM Corp, 2020).

3 | RESULTS

3.1 | Research question 1: Prevalence, living arrangements and staffing level

Overall, 3345 (42.0%) of participants reported that they could stay home if they wanted to, 1293 (16.2%) could sometimes stay home,

TABLE 1 Percentage of people who can stay home by living arrangement ($N = 7968$)

Living Arrangement type	Can stay home?			Total n
	No %	Sometimes %	Yes %	
Own home	26.5	12.0	61.4	1688
Group 2-3	49.1	17.4	33.5	1967
Group 4-6	46.8	19.0	34.3	2979
Group 7-15	37.0	19.2	43.8	792
Institution	42.4	5.7	51.8	542
Total	41.8	16.2	42.0	7968

Note: Row percentages are shown.

TABLE 2 Number and percentage of people who can stay home by staffing level at home ($N = 7968$)

Living arrangement type	24-h staff support at home?	Can stay home?						Statistical comparisons
		No, always has to go		Sometimes		Yes, can stay home		
		n	%	n	%	n	%	
Own home	No ($n = 851$)	94 _a	11.0	78 _b	9.2	679 _c	79.8	$\chi^2 = 261.04$
	Yes ($n = 837$)	354 _a	42.3	125 _b	14.9	358 _c	42.8	$p < .001$
Group 2-3	No ($n = 140$)	36 _a	25.7	22 _a	15.7	82 _b	58.6	$\chi^2 = 45.32$
	Yes ($n = 1827$)	930 _a	50.9	320 _a	17.5	577 _b	31.6	$p < .001$
Group 4-6	No ($n = 119$)	45	37.8	20	16.8	54	45.4	$\chi^2 = 6.89$
	Yes ($n = 2860$)	1348	47.1	545	19.1	967	33.8	$p = .032$
Group 7-15	No ($n = 56$)	17	30.4	12	21.4	27	48.2	$\chi^2 = 1.14$
	Yes ($n = 736$)	276	37.5	140	19.0	320	43.5	$p = .565$
Institution ^a	No ($n = 7$)	2	28.6	2	28.6	3	42.9	$p = .095^a$
	Yes ($n = 535$)	228	42.6	29	5.4	278	52.0	

Note: Row percentages shown. a,b Within rows, numbers with the same subscript letter did not differ significantly at .05, Bonferroni corrected. Only reported for analyses with overall significance of $p < .001$.

^aThree cells in this analysis have an expected count of less than 5, so the value of chi square is not reported. Instead, the probability obtained from Fishers exact test (2-sided) is shown in the final column.

and 3330 (41.8%) always had to go out. Table 1 shows the prevalence of staying home by current living arrangements.

We found a significant overall relationship between staying-home status and living arrangement type, $\chi^2(8) = 457.29$, $p < .001$, $N = 7968$. Overall, own-home residents had the highest percentage (61.4%) who could stay home, followed by institution dwellers (51.8%), group 7-15 (43.8%), with group 4-6 (34.3%) and group 2-3 (33.5%) the lowest.

We investigated this issue further by examining the relationship between current provision of 24-h staff support and staying-home status for each living arrangement type (Table 2).

Table 2 shows that for own-home and smaller group settings (2-3 residents) there was a significant relationship between 24-h staffing and staying at home. Those without 24-h staffing were more likely to be able to stay home if they wanted. The percentage-point difference between those without/with 24-h staffing who could stay home diminished from own home (79.8%-42.8% = 37.0%), to group 2-3 (58.6%-31.6% = 27.0%). This finding seems logical, given that a much larger proportion of own-home residents (50.4%) had less than 24-h staffing, compared to group 2-3 (7.1%). For all the larger settings (group 4-6, group 7-15, institution) there was no comparison that met the adjusted alpha criterion of $p < .0029$. Only 1.1% of institution residents had less than 24-h staff support.

3.2 | Research question 2: Companions on outings

We counted the number of the five community activity types (entertainment, eating out, shopping, doing errands, attending religious services) done with each type of companion. For example, a participant who answered yes to housemates as companions only for shopping

TABLE 3 Mixed linear models of count of number of different types of community activities (of 5) participated in with each type of companion by staying-home status ($N = 6048$)

Companion Type	Can stay home?						<i>F</i>	Pairwise post-hoc comparison with yes can stay home group	
	No, always has to go		Sometimes		Yes, can stay home			Always has to go	Sometimes
	Estimated marginal mean	<i>SE</i>	Estimated marginal mean	<i>SE</i>	Estimated marginal mean	<i>SE</i>		<i>t</i>	<i>t</i>
Alone ^a	0.06	.01	0.09	.02	0.23	.01	67.32***	-11.58***	-6.73***
Friends ^a	0.30	.02	0.43	.03	0.52	.02	39.67***	-8.79***	-2.48
Family ^a	0.72	.03	0.82	.04	0.84	.03	6.13**	-3.37***	-0.44
Housemates ^a	1.43	.03	1.88	.06	1.37	.03	34.55***	1.40	8.18***
Staff	3.44	.03	3.59	.04	3.25	.03	29.59***	5.08***	7.40***

Note: Level of intellectual disability served as a covariate in all analyses. Estimated marginal means control for level of intellectual disability. ** $p < .0029$, *** $p < .001$.

^aLevel of intellectual disability was a significant covariate at $p < .001$.

TABLE 4 Frequency of community activity (low/high) by staying-home status with odds ratios from each logistic regression analysis

Community activity type		Can stay home?							
		Frequency of community activity (low/high)							
		No, always has to go ^a		Sometimes		OR	Yes, can stay home		OR
Low	High	Low	High	Low	High				
Entertainment	<i>n</i>	1726	1099	600	477	1.24	1584	1142	1.12
	<i>n</i> = 6628								
	%	61.1	38.9	55.7	44.3		58.1	41.9	
Eating out ^b	<i>n</i>	1317	1518	480	604	1.05	1248	1478	0.98
	<i>n</i> = 6645								
	%	46.5	53.5	44.3	55.7		45.8	54.2	
Shopping ^b	<i>n</i>	1321	1485	447	631	1.21	1070	1652	1.31***
	<i>n</i> = 6606								
	%	47.1	52.9	41.5	58.5		39.3	60.7	
Errands ^b	<i>n</i>	1664	1110	637	422	0.97	1432	1260	1.29***
	<i>n</i> = 6525								
	%	60.0	40.0	60.2	39.8		53.2	46.8	
Religious service ^b	<i>n</i>	2002	782	809	259	0.80	1949	776	0.99
	<i>n</i> = 6577								
	%	71.9	28.1	75.7	24.3		71.5	28.5	

Note: Level of intellectual disability served as a covariate in all analyses. Frequency of community activity coding - low = 0, high = 1. *** $p < .001$.

^a'No, always has to go' was the reference category.

^bLevel of intellectual disability was a significant covariate at $p < .001$. In all cases milder disability was associated with higher frequency of community activity.

and entertainment had a count of two types of community activities with housemates. We calculated this count using listwise deletion of cases with missing data. Table 3 shows the results of five separate mixed linear modelling analyses examining the relationship between staying home and the count of types of community activities with each type of companion, controlling for level of intellectual disability.

Table 3 shows a pattern across companions that is consistent with the expectation that those who can stay home had more opportunities to go out with different types of companions for community activities, not just housemates or staff. For community activities alone, with friends or with family (i.e., not people participants lived with), a higher count presumably denotes more variety of companions. The post hoc comparisons in Table 3 show that those who always had to go had significantly lower counts of community activity types with each of these companions than those who could stay home (the reference group).

Conversely, going out with housemates or staff should be more common for residents who always had to go, so a lower activity count for such companions may indicate more opportunities to go out with other types of companions. Those who could stay home had a significantly lower count for going out with staff, but for housemates as companions did not differ significantly from those who always had to go.

3.3 | Research question 3: Frequency and variety of community activities

Respondents selected one of the mutually-exclusive frequency responses (0, 1-2, 3-4, 5+ times in the last month) for each activity type. Because it was not possible to assign an appropriate value to the 5+ category and analyse the responses as a continuous variable,

we dichotomized frequency of community activity into low and high. We recoded the monthly frequency as low (0 or 1–2, recoded as 0) or high (3–4 or 5+, recoded as 1). This binary variable served as the dependent variable, with staying-home status and level of intellectual disability as the independent variables. Separate logistic regression analyses were conducted for each community-activity type.

As Table 4 shows, a significantly larger percentage of people who can stay home were in the high frequency group for shopping and errands than people who always have to go out (reference category), with no significant difference between these two groups for entertainment, eating out, or religious services. Effect sizes were small. Level of intellectual disability was a significant covariate ($p < .001$) for eating out, shopping, errands, and religious services. In all cases, milder intellectual disability was associated with being in the high-participation group.

We evaluated the effect of staying-home status on the number of different types of community activities (range = 0–5 of the five types listed in Tables 3 and 4) participated in during the last month using mixed linear models analysis, with level of intellectual disability as a covariate. Controlling for level of intellectual disability, staying-home status was not significantly related to the variety of (number of different) community activities ($F[2, 3691.82] = 5.73, p > .0029$). Level of intellectual disability was a significant covariate ($F = 125.44, p < .001$). Those with milder intellectual disability participated in a wider variety of activities.

4 | DISCUSSION

People with intellectual and developmental disabilities should be able to go out where, when and with whom they prefer, and not be required to accompany co-residents and caregivers simply because they are not allowed to stay home. Among individuals living in US staffed, non-family, multi-client settings, we found that being able to stay home if you want when people you live with go out was available to less than half (42.0%) of adults with intellectual and developmental disabilities. Those who ‘sometimes’ could stay home (18.2%) were a minority, and for more than 80% of participants, being able to stay home was a yes/no phenomenon. These findings reveal a substantial level of the institutional practice of block treatment, even though only 6.8% of participants were currently institution dwellers.

This situation for community participation is clearly incompatible with current US policy, such as the HCBS Final Settings Rule, with its focus on choice of daily activities and companions (Riesen & Snyder, 2019). This finding indicates that there is much to be done by US disability service providers and regulators to achieve compliance with this aspect of the Final Rule. In a later section headed *Implications for Policy and Practice*, we propose several ways to help achieve this.

4.1 | Block treatment

Being required to go on a group outing is an important issue in itself but may have broader implications. Research has shown that block

treatment is manifested in many ways, not just in relation to outings (Bigby, Cooper, & Reid, 2012; Pratt et al., 1980). Individual items assessing different forms of block treatment intercorrelate (Pratt et al., 1980), suggesting that being required to go out on a group outing may be related to other group activities (e.g., required joint meal-time) designed for the convenience of staff. However, we had no data on other types of block treatment, so could not test these relationships empirically.

Bigby, Knox, et al. (2012) found that work practices in poorly performing group homes prioritised staff preferences, convenience, and needs. For example, some staff considered that taking an individual client into the community was unfair on the staff member who remained at home with the other residents, so all staff and residents had to go out together (Bigby, Knox, et al., 2012).

A possible explanation for the presence of institutional practices like block treatment in community living settings may be carryover by former institutional staff of previous institutional working methods. However, the very high levels of staff turnover in US services (Houseworth et al., 2020) and the almost three decades since institutions were the major US residential provider (Lakin & Stancliffe, 2007) both suggest that few current community staff formerly worked in institutions. Therefore, it is unlikely that staff had applied to community-living settings practices they had previously learned in an institution, but instead that block treatment is a persistent feature of the culture of some community-living settings reflecting the staff-centred way they currently function (Bigby, Knox, et al., 2012). If so, block treatment will not simply fade away because, over time, fewer and fewer staff have worked in institutions. Instead, when present, block treatment will need to be consciously eliminated and person-centred approaches substituted. Later in the Discussion we examine the practice implications of our findings, including the need for staff training.

4.2 | Staying home: Relationship to living arrangements, companions, and community activities

Staying home varied considerably by living arrangements, with the highest percentage being those who lived in their own home (61.4%), an environment often considered the least institutional. This result is unsurprising given that half (50.4%) of own-home residents had less than full-time staffing, so they already regularly experienced periods at home without staff. What was superficially surprising was that institution residents (51.8%) had the second highest percentage of being able to stay home. Nearly all institution residents (98.7%) had full-time staffing.

Answering ‘yes, can stay at home’ may mean the person stays home *alone* without staff (Webber et al., 2010), or that more than one caregiver is available, one of whom can also stay home to support the person there. These two factors help explain an otherwise counterintuitive pattern of responses. The higher percentage of ‘yes’ responses from own-home residents likely reflects their greater opportunity and competence at being able to stay home alone safely (competence

acquired in part through regular opportunities to learn and practise these skills). Own-home settings would rarely have more than one staff member available. By contrast, in large residences higher resident numbers require multiple staff. Coupled with a near universal trend to 24-h staffing in these settings, residents could potentially stay home and be supervised because there were several staff on duty simultaneously.

The findings in Table 2 support this interpretation because in smaller settings (own home, group 2–3) those *without* 24-h staffing were significantly more likely to stay home, presumably because they can safely stay home *alone*. The absence of a significant such relationship for larger settings suggests that staying home in these residences was enabled by staff availability to supervise those remaining at home.

The findings regarding companions need brief interpretation. Individuals who can stay home are not required to go out with staff and other residents, so they should be less likely to have staff or housemates as companions on outings, an expectation mostly supported by our results. Logically, a smaller proportion of outings with staff leaves more opportunity to go out alone, with friends or family, as was consistently reflected in our findings. The evidence in Table 3 is about companions for community activities, not choice of companions *per se*. Nevertheless, the results suggest that those who can stay home have more choice of companions than those who are required to go out.

More frequent participation in a wider range of community activities presumably is desirable. When those who can stay home opted to do so, they did not take part in that community activity, yet we found that they participated in outings as often (entertainment, eating out, attending a religious service) or more often (shopping, errands) than peers. Having more access to going out with friends, family or alone may well have resulted in increased opportunities for community activities that (over)compensated numerically for any activities foregone. This proposition is supported by Stancliffe and Anderson's (2017) finding that adults with intellectual and developmental disabilities who exercised in the community alone (i.e., independently) did so much more often than peers who only exercised with others, such as staff or co-residents. Further, Stancliffe et al.'s (2022) study of attending socially-inclusive community groups and religious services showed that such participation was strongly associated with better friendship outcomes and with less loneliness, but the latter outcome was only for evident for those who took part with friends and/or family. Sharing community activities with friends or family is an excellent way to maintain those social connections and strengthen one's social network.

4.3 | Implications for policy and practice: Promoting individual choice of community participation

Being able to stay home provides a concrete strategy to enhance person-centeredness and choice regarding community outings. Naturally, this strategy needs to be complemented by positive efforts to support the person to go out when, where and with whom they choose. In addition, being able to stay home safely will often require direct or indirect caregiver support.

No specific information was available in our study about why people did not stay home (e.g., safety concerns about being home alone; no caregiver available), which limits the capacity to identify and target the specific causes and develop interventions. Data gathered in future research on what particular factors enabled people to stay home if they wanted could potentially inform interventions to facilitate greater person-centeredness and choice. Nevertheless, below we propose several initial practical strategies to enable a more person-centred approach with appropriate safety that could be evaluated in future research.

4.4 | Expanding the options for those who can sometimes choose to stay home

The NCI-IPS data did not reveal how often or under what circumstances people who answered 'sometimes' could stay home. In individual cases, these issues may point to an avenue for intervention to expand opportunities to choose to stay home. For example, a person who is considered able to stay home alone safely for a maximum of 20 min could gradually have this duration lengthened to build experience and confidence.

4.5 | Offering an alternative to going out with co-residents

If the person does not wish to go out with co-residents but cannot safely stay home alone, then alternative support arrangements could be made. Options include more flexible staff scheduling so support is available at home for the period of the outing; alternative activities such as visiting family or friends; or collaborating with other group homes so there is more than one community activity to choose from. These approaches are not fully individualised (e.g., no choice of when) but can offer an alternative to always being required to go out with co-residents.

4.6 | Teaching the person to stay home alone safely

Finding ways for the person to stay home *alone* safely represents an independent response to this issue. This approach could include teaching the individual the skills and safety behaviours needed to stay home alone (Cocks et al., 2016; Webber et al., 2010). Little attention has been paid to this issue, so the literature provides limited guidance. Potential target skills include seeking help when needed, dealing appropriately with visitors and phone calls, and basic safety skills to prevent or respond to home emergencies. As skills and confidence develop, the person could stay home alone for longer periods.

These issues can have far-reaching implications beyond community participation itself. Major life transitions such as moving into one's own home or retiring can be partly contingent on being (seen to be) able to stay home alone safely. For example, Webber et al. (2010) reported that some group home staff in Australia taught the needed

skills to residents so they could stay home unsupervised, which enabled the individuals to implement their wish to retire (the group home did not have staff on duty during the day on weekdays). In other cases where the home-alone option was not offered, the need for the individual to retire was seen as a reason for the person to move to a different group home with 24-h staffing or to transfer to an aged-care facility. Residents had no real say in these decisions (Webber et al., 2010). Sheth et al. (2021) reported similar issues for residents of US residential settings.

4.7 | Staff training

Webber et al. (2010) also reported that some staff were reluctant to leave residents unsupervised, regardless of their competence at staying home alone safely. Training may be needed for staff to recognise block treatment as an undesirable institutional practice and to empower them to appropriately support the choice to stay home. Too often, staff follow the implicit workplace culture and support clients as they have observed other staff doing (e.g., taking everyone shopping as a group; Bigby, Knox, et al., 2012). Staff professional development should emphasise person-centred supports and self-determination (e.g., person-centred thinking and planning; Crisp & Lawrence, 2019) and provide the knowledge and skills to teach the person how to stay home safely if they choose to. In turn, provider-organisation policies that guide staff should strike a sensible balance between freedom and risk, and not simply be risk averse.

4.8 | Using technology

Another option is using remote monitoring and communication technology to provide support and supervision from staff located remotely, services often provided by an organisation specialising in remote monitoring, to enable a person to stay home safely without having staff physically present in the home with them (Tassé et al., 2020). This approach has been utilised more frequently and efficiently in the last decade. HCBS waiver funding is available in US states that have included remote support technologies in their menu of authorised services (Tassé et al., 2020). Tassé et al. proposed that such technology could 'increase individual choice and independence' (p. 644). We had no information about the use of technology in this study, so we could not evaluate its relationship to being able to stay home when other residents go out.

4.9 | Future research

We found a high prevalence of the institutional practice of block treatment in relation to community outings. Other forms of block treatment (e.g., group activities at home, residents attending health appointments together) should also be documented by researchers and compared to the expectations of person-centred policy such as the HCBS Final Settings Rule (Riesen & Snyder, 2019).

Adults who live with family typically are the only person with intellectual and developmental disabilities in the setting, so block treatment in the usual sense (a group of people with disabilities being required to do things together) does not apply. However, the issue can still arise if the person is required to go on family outings because of concerns about their ability to stay home alone safely. This situation needs to be better understood to identify its extent and to consider possible responses to increase the person's choice and control.

Most study participants were white. Future research could examine whether participants from racial or ethnic minorities encounter different opportunities or barriers to staying home/going out or make different choices about staying home alone.

4.10 | Limitations

Our study has several limitations. Between-state differences are common in disability services and service-user outcomes. We aggregated data across 36 states with varying sample sizes, which may have obscured potential effects of state policy differences.

As noted, we only looked at one aspect of block treatment—being able to stay home—albeit an important one with potentially far-reaching implications for the individual. Certain participants were excluded from our analyses. For example, among participants with otherwise complete data, 1263 people lived alone (94.0% in their own home) and therefore were not asked about going out with co-residents. Presumably, they are more likely to be able to stay home and to go out where, when and with whom they choose because there are no co-residents to consider. Thus, our reported prevalence of being able to stay home may be understated and should be interpreted as prevalence for adults with intellectual and developmental disabilities living in staffed, non-family, multi-client settings.

We excluded individuals who responded 'none of the above' to the item about the amount of paid staff support at home. This criterion mainly affected own-home dwellers who had no staff support at home, so it likely understated the difference between 24-h support and less than 24-h support for own-home residents.

5 | CONCLUSIONS

The institutional practice of block treatment persists in many US community living settings. Equally persistent efforts are needed to help identify and minimise this practice, so that adults with intellectual and developmental disabilities can exercise more choice about where, when and with whom they go out, in line with current US disability policy.

ACKNOWLEDGEMENTS

Development of this article was supported by Grant #90RTCP0003 to the Research and Training Center for Community Living from the National Institute on Disability Independent Living and Rehabilitation Research, U.S. Department of Health and Human Services. Grantees undertaking projects under government sponsorship are encouraged to express freely

their findings and conclusions. Points of view or opinions do not therefore necessarily represent official NIDILRR policy. The authors thank the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI) for granting access to the NCI-IPS 2018–19 data.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the Human Services Research Institute. Restrictions apply to the availability of these data, which were used under license for this study. Data are available from <https://www.nationalcoreindicators.org/> with the permission of the Human Services Research Institute (HSRI) and the National Association of State Directors of Developmental Disabilities Services (NASDDDS).

ORCID

Roger J. Stancliffe  <https://orcid.org/0000-0003-4265-7433>

Sandra L. Pettingell  <https://orcid.org/0000-0001-6329-8834>

James Houseworth  <https://orcid.org/0000-0001-9214-5247>

REFERENCES

- Bigby, C., Cooper, B. K., & Reid, K. (2012). *Making life good in the community: Measures of resident outcomes and staff perceptions of the move from an institution*. Victorian Government Department of Human Services <https://vgls.sdp.sirsidynix.net.au/client/search/asset/1262188>
- Bigby, C., Knox, M., Beadle-Brown, J., Clement, T., & Mansell, J. (2012). Uncovering dimensions of culture in underperforming group homes for people with severe intellectual disability. *Intellectual and Developmental Disabilities*, 50(6), 452–457. <https://doi.org/10.1352/1934-9556-50.06.452>
- Cocks, E., Thoresen, S. H., O'Brien, P., McVilly, K., Thomson, A., Gadow, F., Crosbie, J., & Prain, M. (2016). Examples of individual supported living for adults with intellectual disability. *Journal of Intellectual Disabilities*, 20(2), 100–108. <https://doi.org/10.1177/1744629516629854>
- Crisp, S. E., & Lawrence, J. (2019). *Person-centered thinking, planning, and practice: A national environmental scan of foundational resources and approaches*. National Center on Advancing Person-Centered Practices and Systems https://ncapps.acl.gov/docs/NCAPPS_ResourcesApproaches_NationalEnvironmentalScan_December2019.pdf
- Friedman, C. (2020). The impact of home and community based settings (HCBS) final settings rule outcomes on health and safety. *Intellectual and Developmental Disabilities*, 58(6), 486–498. <https://doi.org/10.1352/1934-9556-58.6.486>
- Houseworth, J., Pettingell, S. L., Kramme, J. E. D., Tichá, R., & Hewitt, A. S. (2020). Predictors of annual and early separations among direct support professionals: National Core Indicators Staff Stability Survey. *Intellectual and Developmental Disabilities*, 58(3), 192–207. <https://doi.org/10.1352/1934-9556-58.3.192>
- IBM Corp. (2020). *IBM SPSS statistics for windows, (version 27.0)*. [computer software]. IBM Corp.
- Lakin, K. C., & Stancliffe, R. J. (2007). Residential supports for persons with intellectual and developmental disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 151–159. <https://doi.org/10.1002/mrdd.20148>
- Kozma, A., Mansell, J., & Beadle-Brown, J. (2009). Outcomes in different residential settings for people with intellectual disability: a systematic review. *American Journal on Intellectual and Developmental Disabilities*, 114(3), 193–222. <https://doi.org/10.1352/1944-7558-114.3.193>
- Larson, S. A., Eschenbacher, H. J., Taylor, B., Pettingell, S., Sowers, M., & Bourne, M. L. (2020). *In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2017*. University of Minnesota https://ici-s.umn.edu/files/aCHyYaFjMi/risp_2017
- NCI. (2019a). National Core Indicators® 2018–19 In-Person Survey (IPS) National Report: Appendix B State Sample Frames
- NCI. (2019b). National Core Indicators® 2018–19 In-Person Survey (IPS) National Report: Overview
- Pratt, M. W., Luszcz, M. A., & Brown, M. E. (1980). Measuring the dimensions of the quality of care in small community residences. *American Journal of Mental Deficiency*, 85, 188–194.
- Riesen, T., & Snyder, A. (2019). *A guide to the home- and community-based services (HCBS) final settings rule*. Center for Persons with Disabilities Utah State University <https://ceiutah.com/wp-content/uploads/2020/01/HCBS-Provider-Manual-final.pdf>
- Sheth, A. J., Kramer, J. M., Magasi, S., Heller, T., Nishida, A., & Hammel, J. (2021). “It’s not the same without you”: Exploring the experience and perception of transition for people with intellectual disabilities and dementia. *British Journal of Learning Disabilities*, 49, 365–372. <https://doi.org/10.1111/bld.12412>
- SPSS Inc. (2005). *Linear mixed-effects modeling in SPSS: An introduction to the MIXED procedure* (Technical Report). <https://csass.ucsc.edu/self-study%20courses/SPSSMixed.pdf>
- Stancliffe, R. J., & Anderson, L. L. (2017). Factors associated with meeting physical activity guidelines by adults with intellectual and developmental disabilities. *Research in Developmental Disabilities*, 62, 1–14. <https://doi.org/10.1016/j.ridd.2017.01.009>
- Stancliffe, R. J., Pettingell, S. L., Houseworth, J., & Tichá, R. (2022). Participation in socially-inclusive community activities by adults with intellectual and developmental disabilities. Manuscript submitted for publication.
- Tassé, M. J., Wagner, J. B., & Kim, M. (2020). Using technology and remote support services to promote independent living of adults with intellectual and related developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, 33(3), 640–647. <https://doi.org/10.1111/jar.12709>
- Verdonschot, M. M., de Witte, L. P., Reichrath, E., Buntinx, W. H. E., & Curfs, L. M. (2009). Community participation of people with an intellectual disability: A review of empirical findings. *Journal of Intellectual Disability Research*, 53(4), 303–318. <https://doi.org/10.1111/j.1365-2788.2008.01144.x>
- Weaver, B., & Black, R. A. (2015). Comment on Hoffman and Rovine (2007): SPSS MIXED can estimate models with heterogeneous variances. *Behavior Research methods*, 47, 355–360. <https://doi.org/10.3758/s13428-014-0474-y>
- Webber, R., Bowers, B., & McKenzie-Green, B. (2010). Staff responses to age-related health changes in people with an intellectual disability in group homes. *Disability & Society*, 25(6), 657–671. <https://doi.org/10.1080/09687599.2010.505736>

How to cite this article: Stancliffe, R. J., Pettingell, S. L., Bershadsky, J., Houseworth, J., & Tichá, R. (2022). Community participation and staying home if you want: US adults with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, 35(5), 1199–1207. <https://doi.org/10.1111/jar.13014>