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Current services and outcomes of formerly-institutionalized and never-institutionalized US adults with intellectual and developmental disabilities: A propensity score matching analysis

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Abstract

Background.—Deinstitutionalization research shows better services and outcomes relative to institutional life but has not compared formerly-institutionalized and never-institutionalized service users.

Methods.—We used propensity score matching (PSM) to match formerly-institutionalized and never-institutionalized participants on six personal characteristics. Data came from the 2018-19 National Core Indicators In-Person Survey. We excluded current institution residents, and states with 25%+ of missing data on former institutionalization.

Results.—Overall, 15.5% of participants in the 29-state full sample had lived in an institution for one year or more. Findings from the PSM sample showed that former-institution residents were more likely to use congregate living arrangements and less likely to live with family. They experienced more loneliness, less support-related choice, and had a consistent pattern of disability service-focused social connections.

Conclusions.—Many former institution residents remain disadvantaged relative to matched peers. There is a need to identify factors to enhance services and outcomes following deinstitutionalization.

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Conflict of Interest disclosure

All authors declare that they have no competing interests.

Ethics approval statement

The University of Minnesota's institutional review board (IRB) reviewed this research and granted a waiver of ongoing IRB review and approval.

Introduction

The Deinstitutionalization Era

In the United States (US), the peak institutional population was reached in the late 1960s (Larson et al., 2022). The longstanding US administrative criterion for distinguishing an institution from other non-family residential settings for people with intellectual and developmental disabilities is that institutions house 16 or more people with disabilities. However, historically these settings typically accommodated hundreds or thousands of residents on a self-contained campus. Even though many remaining institutions have been substantially depopulated over time, nationally in 2019 resident numbers in state institutions still averaged 76 (Larson et al., 2022), whereas this average was 261 residents in 1999 (Prouty & Lakin, 2000).

The 1970s and 1980s saw the largest depopulation of institutions as former residents moved to community settings and some institutions closed. In 1977-87, the number of people nationally with intellectual and developmental disabilities living in settings of 16+ people (institutions) fell by 70,253 (33.9% of the 1977 total of 207,356). The equivalent numbers for 1987-97 were 43,741 (21.1%), and for 1997-2007 were 30,866 (14.9%) (Larson et al., 2022). Deinstitutionalization continues today, but far fewer individuals are affected.

Thus, the largest numbers of former institution residents currently living in community settings likely left institutions decades ago. This reality has important implications. First, these formerly-institutionalized individuals likely have markedly different personal characteristics from typical users of contemporary intellectual and developmental disabilities adult services. For example, they would be considerably older, likely with more severe disability (Lakin et al., 1997). Therefore, careful control of relevant personal characteristics is required for fair comparisons with peers who were never institutionalized. Second, the community services available at the time they left the institution differed from what is offered today. In the 1980s and 1990s, the dominant funded models of community living were group homes, often with 6 or more residents (Stancliffe & Lakin, 1998). Individuals leaving an institution in the 1980s or 1990s may have had little alternative but to move to such a congregate community living setting. Unless they subsequently moved to a different type of community housing, many former institution residents may still live in such settings today.

With the advent in 1981 and subsequent massive growth of Home and Community Based Services (HCBS) funding – federal financial assistance to states for providing non-institutional, community-based disability services (Larson et al., 2022) – people with intellectual and developmental disabilities and their families had an alternative to institutions, meaning that new entrants to the service system increasingly have never lived in an institution and nowadays have an array of more individualized community-living options from which to choose, including receiving paid staff support in their own home or family home.

Deinstitutionalization Research

Quantitative deinstitutionalization research typically has made longitudinal comparisons before and after the move to the community, or cross-sectional contrasts between those who moved and those who remained in the institution (Kozma et al., 2009; Larson et al., 2012; McCarron et al., 2019). To date, deinstitutionalization research has given no attention to comparisons with intellectual and developmental disabilities service users who were never institutionalized.

Deinstitutionalization research tells us that those who moved to the community experience greater choice, more community participation, better quality of life, more friends, increased family contact, and improved adaptive behavior (Chowdhury & Benson, 2011; Kozma et al., 2009; Larson et al., 2012; McCarron et al., 2019; Stancliffe & Abery, 1997; Stancliffe & Lakin, 1998). The underlying logic rests on the effects of *environmental* factors, namely that poor outcomes persist in institutions because they are geographically distant from family and friends, self-contained settings segregated from the community, regimented, lacking privacy, and characterized by group treatment not person-centeredness. By contrast, community-living settings offer more domestic and community participation, social inclusion, and individualization, with the resulting participation, social inclusion, and greater person centeredness assumed to lead to the improved outcomes just mentioned. If these effects of the person's living situation are the main factors leading to improved outcomes, then community residents with and without a personal history of institutionalization (operationally defined as having lived for 12 consecutive months or longer in an institutional setting) should experience similar outcomes in comparable community settings. Consequently, one key research question is whether former institution residents have equal access to individualized community living and employment services, such as living in one's own home, and working in community employment. Past institutionalization could be a strong influence on an individual's disability service trajectory over time, so that even with a move from institution to the community, such a history is more likely to place an individual on a more restrictive, congregate service trajectory, albeit in a community setting.

Institutionalization and subsequent use of congregate community services may also have important *social* effects, including loss of family relationships, family social support, and family advocacy for better services. A key purpose of the current paper is to compare adults with intellectual and developmental disabilities with and without a personal history of institutionalization, to determine their current access to community living, community employment, quality of life outcomes such as choice, loneliness, and group treatment, as well as social relationships including friendship, social inclusion in mainstream community groups, and family contact.

Propensity Score Matching

Above, we noted the need to control relevant personal characteristics to enable fair comparisons with peers who were never institutionalized. As our article's title indicates, we used *propensity score matching* (PSM) to match individuals with/without a history of being institutionalized on multiple personal characteristics. PSM is increasingly used in medical research (Amoah et al., 2020), but is rare in intellectual and developmental disabilities

studies (Nicholson et al., 2022). The details of PSM matching are explained in the Method section. Fundamentally, PSM uses logistic regression with the characteristics to be matched serving as independent variables to calculate the likelihood (propensity score) that each participant is in the treatment group (Austin, 2011). Pairs of treatment and comparison participants are matched if they each have a similar (fuzzy match) or identical (match) value of the propensity score (Austin, 2011). Cases are included in PSM analyses only if satisfactory matching is attained, with analyses of PSM samples found to provide more accurate and less biased estimates of treatment effects than regression (Amoah et al., 2020; Martens et al., 2008; Nicholson et al., 2022).

Research Questions

Compared to intellectual and developmental disabilities service users who have never been institutionalized for one year or more, how do people who were formerly institutionalized do on:

- Accessing different types of community living services
- Accessing different types of employment and day activity services
- Exercising everyday choice and support-related choice
- Having friends, experiencing loneliness, being a member of a mainstream community group, attending a religious service, and having various types of companions to go to the group with
- Experiencing group treatment (i.e., having to go when others in your house go out)?

Methods

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

Data and Instrument

The National Core Indicators In-Person Survey (NCI-IPS) (NCI, 2019a) is an annual cross-sectional survey conducted by the National Association of State Directors of Developmental Disabilities Services, the Human Services Research Institute, and intellectual and developmental disabilities agencies in participating US states. First undertaken in 1997, this survey collects data on individual characteristics, service use, and outcomes of random samples of adult service users in each participating state (Bradley & Moseley, 2007).

We used data from all three sections of the NCI-IPS 2018-2019. Participants personal characteristics (age, sex, level of intellectual disability, mental health, challenging behavior, mobility), and services (living arrangements, employment, day programs, and history of institutionalization) came from the Background Information Section. This information usually is taken from case management and service provider records. Sections I and II involve an in-person interview. Items on friendship and loneliness were drawn from Section I of the NCI-IPS, which may only be answered by the person with intellectual and

developmental disabilities (proxy responses are not accepted), so these data were missing for individuals who did not self-report. Data from NCI-IPS Section II included the choice items, and questions about participation in mainstream community groups and religious services, including about companions for these activities. Section II also contained the item on being able to say home if you want. Respondents to Section II were the individual receiving services where possible or, if the person is unable or unwilling, family, an advocate, or staff.

State Selection and Missing Data

For NCI-IPS data, National Core Indicators reports use a convention of 25% or more of missing data (e.g., don't know, missing) for an item within a state sample to flag the state's data for that item as potentially unrepresentative (NCI, 2019a). Two states (MN, WI) reported no data on NCI-IPS participants' individual history of institutionalization, but the remaining 35 states did so. We adopted the NCI convention but went a step further and excluded from our analyses states with 25% or more missing data for the history of institutionalization item. This approach resulted in the omission of six states (CO, DE, KS, NY, OR, WY) that had missing data rates ranging from 29.1% (CO) to 99.0% (OR) of participants, with an unweighted mean of 53.2%. The remaining 29 states (AL, AR, AZ, CT, FL, GA, HI, IN, KY, ME, MI, MO, NC, NE, NH, NJ, NV, OH, OK, PA, RI, SC, SD, TN, TX, UT, VA, VT, WA) had missing data rates ranging from 0.0% (OK) to 23.5% (RI).

Propensity Score Matching

The following six personal characteristics served as PSM matching keys: age group, sex, level of ID (dummy coded), challenging behavior, mental health, and mobility. We chose these personal characteristics either because they are basic demographic variables (sex) or have been shown in previous research to relate to outcomes of interest such as choice (Stancliffe et al., 2011; Tichá et al., 2012), employment (Stancliffe et al., 2019), living arrangements (Stancliffe et al., 2011), loneliness (Stancliffe et al., 2007, 2009, 2010), and socially-inclusive community participation (Stancliffe al., in press). Importantly, age mirrors life history, with older participants having vastly different past access to education, employment, disability services and many other opportunities relative to younger people with intellectual and developmental disabilities. Finally, given the logic of our analyses, it was inappropriate to use environmental variables, such as living arrangements, for matching because deinstitutionalization is an environmental intervention and community living arrangements are a direct outcome of this intervention.

PSM match tolerance was .02. Overall, there were 1818 formerly-institutionalized participants with complete data on the matching keys. Of these, 1688 (92.8%) had an individual match among the never-institutionalized participants, yielding a total PSM sample of N=3376. There were 194 exact matches, 1494 fuzzy matches, and 130 (7.2%) formerly-institutionalized participants were not matched. The mean propensity scores for those formerly institutionalized (0.276) and never-institutionalized (0.273) did not differ significantly, $t(3374)=0.43$, $p=.67$, Cohen's $d = 0.02$, indicating an excellent overall match.

Participants

Participating states survey a random sample of adults with intellectual and developmental disabilities, aged 18 years or older, who received at least one funded disability support service from the state DD system in addition to case management. Each state must achieve a sample that reaches the 95% confidence level and 5% margin of error threshold based on the size of the sample frame. Each state's sampling strategy can be found in Appendix B in NCI's 2018-2019 IPS Final Report (NCI, 2019b).

The state selection processes described above resulted in an overall sample of 16,236 participants. Because we planned to compare *former* institution residents with peers who had *never* been institutionalized, we omitted *current* institution residents (N=573) from our analyses. Given that current community living arrangements were of interest, we also omitted people whose residential setting was coded as "other" or missing because the nature of their living arrangements was unclear. These criteria left a sample of 15,368 of whom 1548 (10.1%) had missing data for the history of institutionalization item, leaving an analyzed full sample with non-missing data of 13,820. State full sample sizes ranged from 273 (RI) to 1572 (TX), averaging 476.6. State PSM sample sizes ranged from 19 (WA) to 448 (TX). Table 1 reports descriptive statistics for the PSM matching variables and between-group comparisons for the full sample and for the PSM sample.

Age.—For the full sample, formerly-institutionalized participants (mean=51.7, SD=15.5 years) were significantly older than those never institutionalized (mean=39.7, SD=14.2 years), $t(2816.4)=33.15$, $p<.001$, Cohen's $d=0.83$. For the PSM sample, mean age did not differ significantly for those formerly (mean=51.1, SD=15.1 years) and never institutionalized (mean=50.4, SD=14.7 years), $t(3374)=1.48$, $p=.14$, $d=0.05$.

Table 1 shows that, for the full sample, those formerly institutionalized were more likely to be male, have more severe ID, challenging behavior, a mental health condition, and mobility difficulties. That is, each of these six personal characteristics was confounded with group membership, so these variables needed to be controlled to yield meaningful between-group comparisons of services and outcomes. In such circumstances PSM is an effective technique for creating equivalent groups for analysis. Table 1 shows that for the PSM sample the two groups did not differ significantly on any six personal characteristic and effect sizes were tiny, providing consistent evidence of an excellent match.

Variables

History of Institutionalization—This NCI-ICS item asks, "Has this person ever lived in an institutional setting for longer than a year?" (NASDDDS & HSRI, 2018, p. 19). Instructions clarify that this period means at least 12 consecutive months in an institutional setting.

Personal characteristics

Level of intellectual disability.: This item 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.

Challenging behavior.: A single item asking if the person has behavior challenges (e.g., aggression, self-injurious behavior, pica, etc.) noted on their record.

Mental health condition.: Three NCI-IPS items respectively asked about mood, anxiety, or psychotic disorders being noted on the person's record. The presence of one or more of these conditions was coded "yes" and the absence of all three was coded "no".

Mobility.: The NCI-ACS mobility item has three response options which we recoded into two categories: independently mobile without aids versus uses aids/not mobile.

Services

Living arrangements.: This NCI-IPS item had 14 mutually-exclusive response options for living-arrangement type, which we recoded into 8 categories, 6 of which were used in the current study: (a) Own home (may be owned, rented, or shared with spouse or roommates), (b) family member's home, (c) foster/host home (a single-family residence where one or more persons with disability live with a person/family who provides services), and the following settings each operated by a service provider agency (d) Group 2-3, (e) Group 4-6, and (f) Group 7-15 (group living settings for the specified number of people with disabilities, regardless of funding source). The "other" living arrangements category was omitted because the nature of living arrangements were very varied or unknown.

Community employment.: Community-based settings are where most co-workers do not have disabilities. We included (a) paid individual jobs in the regular labor market (competitive employment), and (b) paid employment in an integrated setting as part of a group of 8 or fewer people with disabilities (e.g., enclave, work crew).

Facility based employment.: Includes traditional sheltered workshops or work activity centers that provide paid work activity for people with disabilities.

Community activities was coded yes if the person participated in unpaid community-based activities.

Facility-based activity was coded yes if the person did unpaid activities in a facility-based setting for people with disabilities.

No formal day activities.: Individuals with no formal day activities were those who did not use any of the four types of employment/day activity listed above.

Because participants could take part in more than one type of employment/day activity, these variables were each analyzed separately.

Outcomes

Choice.: We used two multi-item choice scales: *support-related choice* (5 items) and *everyday choice* (3 items) (Tichá et al., 2012). Scale scores were calculated by averaging individual item scores provided at least 60% of the scale questions had been answered. Range for both scales was from 0 (no choice) to 2 (full choice). Items for the support-related choice were (a) where to live, (b) people you live with, (c) the place you work or your day program or workshop, (d) changing your case manager, and (e) your staff. The everyday choice items were (a) your daily schedule, (b) how you spend your free time, and (c) what you buy with your spending money. Response options for each item were: the person chooses (score=2), person has some input or has help choosing (score=1), someone else decides (score=0).

Friendship.: This item asked, “Do you have friends you like to talk to or do things with?”

Loneliness.: There was a single item asking “Do you ever feel lonely?”

Community group participation and religious-service attendance items are from the *Community Inclusion* section of NCI-IPS Section II. Instructions to interviewers specify that the survey intends to assess whether “the person participates in integrated community activities (activities that include people with and without disabilities)” (NASDDDS & HSRI, 2018, p. 49).

Community Groups.: The question states “Are you a part of any community groups? (This includes church groups, book clubs, knitting groups or any other formal or informal community group in an inclusive setting.)” (NASDDDS & HSRI, 2018, p. 50). Interviewers can also provide other individually relevant examples of community groups. The next question, “Who did you participate in community groups with?” (p. 51), has six response options: (a) Alone, (b) Friends, (c) Family, (d) Housemates or coworkers, (e) Staff, and (f) Others not listed. Respondents may choose all that apply.

Religious Services.: The NCI-IPS asks “How many times did you go out to a religious service or spiritual practice in the past month? (Examples: church, synagogue, study, or other place of worship)” (NASDDDS & HSRI, 2018, p. 53), with four mutually exclusive response options of (a) Did not go, (b) 1–2 times, (c) 3–4 times, and (d) 5 or more times. We recoded religious-service attendance variable into a yes/no variable. The question about whom the person usually goes with, is similar to this question for community groups.

Group treatment.: This single item asks “(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?” (NASDDDS & HSRI, 2018, p. 60).

Analyses

All analyses were undertaken using SPSS v27. We used a two-stage analytic approach. In stage 1, we use the full sample to calculate the prevalence of having previously been institutionalized, and to compare personal characteristics between the formerly-

institutionalized and never-institutionalized groups, using descriptive statistics, *t*-tests or Chi- square as appropriate to the level of measurement.

In the second stage, we used PSM (Austin, 2011) to create a smaller matched sample to control for the confounding effects of the large between-group differences in personal characteristics. We used PSM available in SPSS v27 complete with Python Essentials and the FUZZY extension command. We used age group, sex, level of intellectual disability, challenging behavior, mental health, and mobility as the matching key variables to calculate the propensity scores (risk) of having formerly been institutionalized. Participants with missing data on one or more of these matching variables were excluded from the matching computations and consequently were not included in the PSM sample. The propensity scores were used to match a never-institutionalized participant with a formerly-institutionalized participant as either an exact match or a fuzzy match (within a specified match tolerance of 0.02). The robustness of the matching was checked by comparing the two group's propensity scores, and by separately comparing the six individual characteristics used to calculate propensity scores.

For some NCI-IPS items, respondents could select all response categories that applied. This situation applied to (a) types of employment and day program participation, and (b) type of companion for community group or religious service participation. Consequently, each type was analyzed separately, because the categories were not mutually exclusive.

We report standardized mean difference (*d*) as an index of effect size. Because SPSS does not report this statistic or some types of analysis (e.g., Chi-square) we used Wilson's (n.d.) online effect size calculator. Standardized mean difference is the same as Cohen's *d* and can be interpreted in the same manner, namely small effect size ($0.2 \leq d < 0.5$), medium ($0.5 \leq d < 0.8$), and large ($d \geq 0.8$) (Cohen, 1986).

Because we report 19 comparisons of services and outcomes (Tables 2–4 and choice analyses) we used Bonferroni adjustment to control for experimentwise error rate by employing an alpha of .05/19 = .003.

Results

Overall, 2137 (15.5%) of the 29-state full sample had lived in an institution for one year or more. Prevalence of institutional history by state ranged from 3.9% (FL) to 41.5% (OK), with a state median of 14.6%. Further examination of between-state differences was beyond the scope of the present study. All subsequent analyses of services and outcomes used the PSM sample.

Services and Outcomes

Living Arrangements—There were notable differences in living arrangements by history of institutionalization. The alphabetic subscripts in Table 2 show that the two groups differed significantly on all living arrangements except own home and Group 2-3. One third of the never-institutionalized group lived with family compared to only 6.3% of those who

had formerly been institutionalized. Conversely, those who had been institutionalized were significantly more likely to live in larger group settings or a foster/host home.

Employment and Day Activities

As Table 3 shows, there was no significant relationship between history of institutionalization and participation rate in any type of employment or day program except for unpaid facility-based activities where those formerly institutionalized (46.4%) were significantly less likely to participate than the never-institutionalized group (53.8%), but the effect size was very small (d=−0.15).

Choice

Everyday Choice.—Cronbach's alpha was .72. Independent t-test comparison revealed a small group difference showing that the never-institutionalized group (mean=1.45) had more choice than the formerly-institutionalized group (mean=1.40), $t(3315)=2.66$, p=.008, Cohen's d=−0.09. However, this difference did not meet the revised alpha of p<.003, so was not considered significant.

Support-related Choice.—Cronbach's alpha was 0.70. We found a significant group difference showing that the never-institutionalized group (mean=1.04) had significantly more choice that the formerly-institutionalized group (mean=0.85), $t(2923)=9.62$, p<.001, Cohen's d=−0.36. This is a much larger effect size than for everyday choice.

Social Network, Loneliness and Community Participation

We examined multiple indicators of the person's social outcomes (a) having friends, (b) feeling lonely, (c) community group membership, (d) religious service participation, and (e) the companions (family, housemates, or staff) with whom they participated in these community activities. Lastly, we compared group treatment, as indicated by whether the person always had to go when others in their home went out or could stay home if they wanted to.

Having friends did not differ significantly by group. More formerly-institutionalized people frequently experienced loneliness, with 16.3% who often felt lonely, as opposed to 7.5% of the never-institutionalized group. Participation rates in mainstream community groups and religious services did not differ significantly. However, the type of companion for each activity type revealed a clear and consistent pattern of disability service focused social connections for those who had been institutionalized versus a more family focused social network for the never-institutionalized group. For both types of socially inclusive activity, those formerly institutionalized were significantly less likely to have family as companions, and significantly more likely to have housemates and staff companions, with notable effect sizes.

Group Treatment.—Group treatment (always having to go when others in your house go out) tended to be more prevalent among those formerly institutionalized, but at p=.004 did not meet the revised alpha of p<.003.

Discussion

Among current adult intellectual and developmental disabilities community service users in 2018-19 from 29 US states, we found that 15.5% had formerly lived in an institution for one year or more. Prevalence varied markedly by state, likely reflecting each state's history of institutional provision and subsequent deinstitutionalization. Most adult community service users (84.5%) had no such institutional history, a statement that was true for residents of all types of community living arrangements (we excluded current institution residents). Nationally in 2018, only 4.8% of people with intellectual and developmental disabilities receiving long-term services and supports currently lived in institutions with 16+ residents, with 9 states (including 5 states in the current study) having no residents in such facilities (Larson et al., 2021). Taken together with our findings, these figures show that deinstitutionalization has become incrementally less relevant to a service system increasingly dominated by HCBS-funded, community-based living options serving people who have never been institutionalized.

As expected, the formerly-institutionalized group was substantially older, much more likely have severe or profound intellectual disability, to have challenging behavior, and a mental health challenge, a little more likely to be men, and less likely to be independently mobile without aids. Because of these consistent differences in personal characteristics, many with notable effect sizes, we used PSM as a rigorous method of creating comparable groups, resulting in very well-matched groups that did not differ an any of the six personal characteristics used to calculate propensity scores.

Consistent with the expectation that most former-institution residents exited the institution decades ago, we found they were more likely than their never-institutionalized peers to use congregate living arrangements, the type of community living settings more commonly available when they moved (Larson et al., 2021).The formerly-institutionalized group experienced several worse quality of life and social outcomes (e.g., more loneliness, less support-related choice), with notable effect sizes. Outcomes including everyday choice ($p<.008$) and group treatment ($p<.004$) were also consistent with this pattern but did not quite satisfy our stringent revised alpha of .003.

Current access to employment and day programs (except facility-based day activities) was similar to the never-institutionalized group. Likewise, the groups did not differ on participation in mainstream structured community activities (community groups, religious services). Overall, these findings likely indicate that service providers achieved similar results when enrolling participants with or without a history of institutionalization into formal, structured activities, be they disability specific or mainstream groups. Unfortunately, this similarity was reflected in equally poor employment outcomes. The sole finding favoring former-institution residents was their significantly lower rate of using segregated, facility-based day activities. This finding was not explained by a difference in rate of having no formal day activities. The reasons for the former result are unclear, but the effect size was small, and use of these segregated day programs was by far the most prevalent type of day activity for both the formerly-institutionalized and never-institutionalized groups.

While access to mainstream community groups and religious services was similar for both groups, we found a consistent pattern of disability service-focused social connections for formerly-institutionalized individuals who were substantially less likely to go to these activities with family (d=−0.37 and −0.55, respectively) but much more likely to go with housemates (d=0.36 and 0.45) or staff (d=0.19 and 0.48). This pattern likely arose in part from their more disability service-focused living arrangements and their vastly lower likelihood of living with family. We might label this phenomenon the *disability service life track* and identify institutionalization/ deinstitutionalization as one gateway to such a service life. Disability service-focused social relationships, such as with disability staff, are not necessarily undesirable, but most are transient due to the very high staff turnover rates in the US (Houseworth et al., 2020). By contrast, family social connections are usually life long, and consequently more important. These differing patterns of social connections may also be related to the loneliness outcomes, consistent with Stancliffe et al.'s (2007, 2010) findings that adults with intellectual and developmental disabilities who had more contact with friends and family reported less loneliness.

Living Arrangements

Many institution survivors continued to experience disadvantage regarding living arrangements. Few former institution residents currently lived with family, strongly suggesting that it is rare for a person to return to the family home after being institutionalized. With an average participant age over 50, the few formerly-institutionalized participants who do currently live with family likely will move out in the future due to parental age-related health problems or death.

Formerly-institutionalized individuals were more likely to currently live in larger, congregate community settings. As noted, when moving from the institution in the past, large congregate community living settings were more common, making it more likely that movers would relocate to such a setting. For example, in 1998, community settings with 7-15 residents made up 16.1% of the funded community living sector, whereas by 2018 such settings constituted only 5.8% (Larson et al., 2021). Consequently, for individuals leaving an institution today, the type of setting they move to may well differ from our findings. Contemporary community living options differ from the past, so current-day institution leavers would be correspondingly less likely, for example, to move to a setting of 7-15 residents.

It is more difficult to infer if a larger percentage of movers today would move to live with family. We found very few former institution residents currently lived with family, but between 1998 and 2018, there was almost sixfold growth in the number of people with intellectual and developmental disabilities living with family with funded in-home support (Larson, 2021). It is unknown if the availability of such support would enable more families to share their home with a formerly-institutionalized family member. Future, policies, funding, and research should explore this option.

Importantly, formerly-institutionalized individuals were just as likely to live in their own home. For those who relocated to the community many years ago, the option of support to live in your own home was less available (Larson et al., 2021). Thus, we presume that

an unknown number likely moved first to congregate community accommodation before subsequently moving to their own home. This inference suggests that such transitions are possible, and that former institution residents need not necessarily be locked in to congregate community living. Future research should examine the transition to one's own home to identify the supports, policies, and funding that enable this move to occur. In addition to information about current living arrangements, such research would be aided by having data on when individuals moved from the institution, what type of setting they moved to, and any subsequently moves to a different type of community living setting. Unfortunately, this information was not available to the current study.

Implications

These findings can be viewed in two ways. From the perspective of former institution residents, in addition to having endured institutional existence, they continue to be disadvantaged after leaving the institution relative to their non-institutionalized peers, being more likely to live in congregate settings, to have poorer outcomes regarding loneliness and choice, and to have more disability service-focused social connections. Thus, one implication of our study is for service systems to address these problems for this population.

A complementary interpretation is that contemporary HCBS services likely result in relatively better outcomes for individuals entering the service system without experiencing institutional life. The community living supports available to service users today, especially living with funded support with family or in one's own home, are fundamentally different from the small or large group homes to which many institutional residents moved at the peak of the deinstitutionalization era in the 1980s and 1990s. Moreover, today's more individualized living arrangements are consistently associated with better outcomes (Oliver et al., 2022). Arguably, the combination of more individualized living arrangements and no institutionalization has resulted in an objectively improved service system with better outcomes for service users. However, we also found that some services and outcomes did not differ by having been institutionalized or not, with frustratingly poor employment outcomes for both groups. Thus, although services and outcomes may have advanced relative to past decades, there remains considerable room for further improvement.

Future Research

We had no baseline (pre-institutionalization) data to enable us to assess the psychological impact of institutional living. Experiencing adverse life events, such as separation from family, loss of other important relationships, or being the victim of abuse or assault, is associated with mental health issues such as depression and post-traumatic stress disorder in people with intellectual and developmental disabilities (Wigham et al., 2013). If institutionalization has long-term psychological effects, then former institution residents may experience worse psychological outcomes than never- institutionalized peers. These issues need careful examination to identify the existence and consequences of such problems.

Randomized control trials (RCTs) are considered the gold standard research design. However, there are many situations in intellectual and developmental disabilities research

where RCTs are not feasible or ethically acceptable. In such cases observational data are often the best available. Using PSM for observational data provides important benefits relative to regression-based approaches in controlling confounding variables (Amoah et al., 2020; Martens et al., 2008; Nicholson et al., 2022). To date, PSM has rarely been used in intellectual and developmental disabilities research. In future, researchers analyzing observational data should carefully consider employing PSM.

Strengths and Limitations

Our study used cross-sectional, observational data, but PSM provided excellent control of the personal characteristics used to calculate propensity scores, so providing well-controlled estimates of effects. However, only variables that are measured and used for matching are controlled (Amoah et al., 2020). For example, we had no data on the amount or quality of support from family over time, a factor that may have influenced initial institutional admission and eventual transfer to community living, and have coloured the experience of institutional life and post-institutional community living.

Ideally, PSM is undertaken using *baseline* participant characteristics for matching. Baseline data (obtained prior to the institutional placement of the formerly-institutionalized group) were not available to us, so we used current data on characteristics for PSM. Some characteristics (sex, level of ID) likely changed little over the years, whereas others (mental health, challenging behavior, mobility) may well have altered with time. Even so, the PSM procedures used the same data for both groups so there was no systematic bias. However, it is possible that some behavioral and mental health factors were affected by the experience of institutionalization.

We did not examine the type of institution the person had lived in (e.g., state-operated, private, nursing home). We had no data on the characteristics of the institution (size, location) or when the individual was exposed to it (e.g., age at entry or exit). The history of institutionalization item asked about living in an institution for 12 consecutive months, so our never-institutionalized group could include some who had been institutionalized for a shorter period. Historical and current differences by state in the past scale of institutional provision, in the timing and extent of deinstitutionalization, and in the nature of community intellectual and developmental disabilities services would have influenced results within individual states. It was beyond the scope of the current study to examine differences between states.

We had no data on the length of institutionalization greater than one year, so we were unable to determine if more time institutionalized was associated with outcomes. Likewise, there was no data on how recently each person left the institution, so we could not evaluate whether longer exposure to community environments had an increasingly beneficial effect.

Conclusions

Moving out of an institution is the start of a new community living journey. Many former institution residents remain disadvantaged relative to their peers and live a more service-focused life as reflected in their congregate living arrangements and greater reliance on housemates and disability staff as companions for community participation. We need to

investigate ways to enable these people to move from larger community settings to more individualized arrangements such as their own home if they wish to, so that they continue to benefit from contemporary improvements to available services. We endorse Chowdhury and Benson's (2011, p. 256) call for more research on identifying "the factors that are critical in enhancing QoL of participants in community-based care following deinstitutionalization".

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Table 1

Personal characteristics (PSM matching variables) by group and by sample

Personal characteristic/Level	Full sample *N*=13,820					Propensity-score matched sample *N*=3,376				
	History of Institutionalization					***History of Institutionalization***				
	Yes %	**No %**	**Total %**	X^2	***d***	**Yes %**	**No %**	**Total %**	X^2	***d***
Sex				11.73***	0.09				0.21	0.02
Male	61.4_a	57.4_b	58.0			59.7_a	60.4_a	60.0		
Female	38.6_a	42.6_b	42.0			40.3_a	39.6_a	40.0		
Level of ID				411.60***	0.47				2.63	−0.02
Mild	33.2_a	43.6_b	41.9			35.9_a	34.2_a	35.1		
Moderate	28.9_a	36.7_b	35.4			31.3_a	33.5_a	32.4		
Severe	19.3_a	13.5_b	14.5			19.5_a	18.5_a	19.0		
Profound	18.6_a	6.1_b	8.3			13.3_a	13.7_a	13.5		
Challenging behavior				328.09***	0.48				0.35	−0.02
No	53.5_a	73.3_b	70.2			55.1_a	56.1_a	55.6		
Yes	46.5_a	26.7_b	29.8			44.9_a	43.9_a	44.4		
Mental health condition				231.31***	0.42				0.00	−0.00
No	34.6_a	52.9_b	50.0			36.4_a	36.5_a	36.5		
Yes	65.4_a	47.1_b	50.0			63.6_a	63.5_a	63.5		
Mobility				103.28***	0.29				0.54	0.03
Uses aids/not mobile	30.0_a	20.1_b	21,7			28.0_a	26.9_a	27.5		
Independently mobile without aids	70.0_a	79.9_b	78.3			72.0_a	73.1_a	72.5		

Note. Column percentages shown. *D* Standardized mean difference.

*** $p<.001$

Table 2

History of Institutionalization by Current Living Arrangements

Current Living Arrangement	Propensity score matched sample		
	Ever lived in an institution?		
	Yes %	No %	χ^2
	***n*=1688**	***n*=1688**	**435.83*** *N*=3376**
Own home	16.8[a]	19.1[a]	
Family home	6.2[a]	32.1[b]	
Foster/host home	9.8[a]	6.6[b]	
Group 2-3	19.1[a]	17.4[a]	
Group 4-6	37.5[a]	19.6[b]	
Group 7-15	10.6[a]	5.2[b]	

Note. Column percentages shown. Standardized mean difference not calculated because Wilson (n.d.) specified that the categories must be at least ordinal.

[a,b], Within rows, cells with the same subscript letter did not differ significantly at .05, Bonferroni corrected.

*** $p<.001$

Table 3

Percentage Currently Participating in Each Type of Employment or Day Activity by History of Institutionalization

Employment/day activity	Propensity score matched sample				
	Ever lived in an institution?				
	Yes %	No %	X^2	*N*	*d*
Community employment	11.5	10.4	0.88	3193	0.03
Facility-based employment	13.5	10.9	4.92	3181	0.08
Community day activities	22.5	18.8	6.71	3231	0.09
Facility-based day activities	46.4	53.8	17.92***	3214	−0.15
No formal day activities	23.6	25.5	1.49	3210	−0.04

d Standardized mean difference

*** $p<.001$

Table 4

Chi Square Comparisons of Social Outcomes by History of Institutionalization

Social outcome	Propensity score matched sample				
	Ever lived in an institution?				
	Y%	N%	X^2	*N*	*d*
Has friends[c]			6.46	2291	−0.04
No	7.6[a]	8.2[a]			
Yes (staff/family only)	15.6[a]	12.0[b]			
Yes	76.8[a]	79.8[a]			
Feels lonely[c]			40.21***	2193	0.21
No	50.8[a]	56.1[b]			
Sometimes	33.0[a]	36.4[a]			
Yes often	16.3[a]	7.5[b]			
Community group membership			0.73	3261	0.03
No	67.8 [a]	69.2[a]			
Yes	32.2 [a]	30.8[a]			
Companions for community groups[f]					
Family			33.94***	1010	−0.37
No	79.4 [a]	62.8 [b]			
Yes	20.6 [a]	37.2 [b]			
Housemates			32.58***	1010	0.36
No	63.1 [a]	79.4 [b]			
Yes	36.9 [a]	20.6 [b]			
Staff			9.17**	1010	0.19
No	31.7 [a]	40.8 [b]			
Yes	68.3 [a]	59.2 [b]			
Religious service participation			3.58	3234	0.07
No	53.9[a]	57.2[a]			
Yes	46.1[a]	42.8[a]			
Companions for religious services[f]					
Family			101.17***	1432	−0.55
No	73.7[a]	47.8[b]			
Yes	26.3[a]	52.2[b]			
Housemates			68.25***	1432	0.45
No	63.1[a]	82.7[b]			
Yes	36.9[a]	17.3[b]			
Staff			78.59***	1432	0.48

Social outcome	Propensity score matched sample				
	Ever lived in an institution?				
	Y%	**N%**	***X²***	***N***	***d***
No	32.7[a]	56.0[b]			
Yes	67.3[a]	44.0[b]			
Group treatment (can stay home)			10.90	3302	−0.11
Always has to go	53.0[a]	48.4[b]			
Sometimes can stay home	16.6[a]	15.6[a]			
Yes can stay home	30.4[a]	36.0 [b]			

[a,b]Within rows, numbers with the same subscript letter did not differ significantly at .05, Bonferroni corrected.

[c]These items come from Section I of the NCI-IPS that may only be answered by self-report, hence the much smaller sample size due to data missing from participants unable to self-report.

[f]Only participants who attended community groups or religious services were asked about their companions for these activities.

d Standardized mean difference

*** $p<.001$

** $p<.003$