

Running Head: Trend change in nursing home census

Trend Change in the Intellectual Disability Nursing Home Census from 1977 to 2004

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Abstract

The Omnibus Budget Reconciliation Act (OBRA) of 1987 was expected to reduce inappropriate residential placements of persons with intellectual disability (ID) in nursing homes. Utilizing the nationally representative 1977, 1985, 1995, and 2004 National Nursing Home Surveys, we estimate trend change in the ID nursing home census pre- and post-OBRA. We find a marked decrease in number and percentage, and shift in the age distribution of the ID nursing home census, most pronounced between 1985 and 1995. We contend that these trend changes, concurrent with growth in the overall nursing home population, provide empirical evidence that policy changes that occurred during the OBRA enactment period were successful in reducing inappropriate residential placements of persons with ID in nursing homes.

Key Words: *intellectual disability; nursing home; OBRA; age; population change*

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Background

Efforts to move persons with intellectual disability (ID) out of state hospitals during the 1960s (Mechanic & Rochefort, 1990) were largely influenced by the deinstitutionalization movement that commenced in the mid-1950s (Lerman, 1985). The process of deinstitutionalization for persons with ID was accelerated with the advent of Medicaid in 1965, through which states began to reimburse nursing homes instead of public hospitals for the care of persons with ID (Lerman, 1985; Mechanic & McAlpine, 2000). Coupled with the glacial development of community-based residential programs, this change in Medicaid reimbursements resulted in the relocation of many persons with ID from state institutions into residential placements in nursing homes during the 1960s and 1970s (Bassuk & Gerson, 1978; Lakin, Hill, & Anderson, 1991; Mechanic & McAlpine, 2000).

The Omnibus Budget Reconciliation Act of 1987 (OBRA) was enacted partially in response to criticism that the expanding population of nursing home residents with ID were not receiving appropriate care (R. L. Anderson & Lewis, 1999; Lakin et al., 1991). OBRA established regulations to ensure that nursing home residents with ID were appropriately placed in settings on the basis of actual care needs, as opposed to being inappropriately placed for the sake of expediency (Braddock et al., 2015; Lakin et al., 1991). In order to be considered a resident of a nursing home based on OBRA regulations, persons with ID must either: 1) require “skilled nursing care”; or 2) be a resident of a nursing home for at least 30 months prior to the implementation of OBRA and choose to retain residence in the nursing home (Eichmann, Griffin, Lyons, Finkel, & Larson, 1992; Lakin et al., 1991). To ensure that all placements of persons with ID in nursing homes were appropriate, OBRA required implementation of a Pre-

Admission Screening and Resident Review (PASRR), as well as an annual review to assess the compatibility between care needs of persons with ID and care services provided by nursing homes (Requirements for States and Long Term Care Facilities, 2017). In addition, similar to requirements for Intermediate Care Facilities for persons with developmental disability, nursing homes were required to more thoroughly address the service needs of residents with ID through active treatment, habilitation plans, case management services, and individualized programs of care (Mitchell & Braddock, 1990; Spreat, Conroy, & Rice, 1998). Incompatibility between the care required by the person with ID and the care provided by the nursing home was intended to result in disapproval of the nursing home as an appropriate residential setting (Eichmann et al., 1992).

Evidence suggests that the ID nursing home census decreased dramatically during the years immediately following the passage of OBRA. While reasonable to think that OBRA was the decisive policy change that resulted in a reduction of the ID nursing home census, it is important to realize that other legislation and policies enacted preceding and concurrent with OBRA presumably informed this trend change. Although coordinated efforts to improve the quality of life for persons with ID in the U.S. began as early as the 1940's, substantial legislative and policy achievements occurred beginning in 1970s (Carey, 2010; Gould, Heller, & Harris, 2012). Prominent achievements include passage of the Rehabilitation Act of 1973, PL 94-142 in 1975, the Rehabilitation Act Amendments of 1986, and the Americans with Disabilities Act (ADA) and the Individuals with Disabilities Education Act (IDEA) in 1990 (Gould et al., 2012). Each of these legislative achievements, as well as many others not listed here, expanded the opportunities for persons with ID to receive supportive care in the “least restrictive environment” in unique ways. In doing so, they also doubtless indirectly contributed to a reduction in the ID

nursing home census. Recognizing that trend change in the ID nursing home census was likely informed by the combination of the enactment of OBRA with other legislative and policy changes preceding and concurrent with OBRA, going forward we intentionally discuss change in the ID nursing home census that occurred pre-OBRA, during the “OBRA enactment period,” and post-OBRA.

Extant estimates of the ID nursing home census pre-OBRA (D. J. Anderson, Lakin, Bruininks, & Hill, 1987; Hing, 1981; Lakin et al., 1991; Sirrocco, 1987) and post-OBRA (Braddock, 1999; Braddock, Hemp, Fujiura, Bachelder, & Mitchell, 1989, 1990; Braddock, Hemp, Tanis, Wu, & Haffer, 2005, 2017; Scott, Larson, & Lakin, 2009) detail a severe reduction during the OBRA enactment period. Despite indication of a decline in the ID nursing home census, there are three empirical concerns regarding the utilization of this disparate data to analyze trend change over time. First, these data do not describe the same population. The pre-OBRA estimates describe nursing home residents with ID. In comparison, the post-OBRA reporting includes the population of nursing home residents with I/DD. Since I/DD is a larger diagnostic umbrella and has a higher prevalence rate than ID (Larson et al., 2001), it is not possible to make valid comparisons of actual change in the ID nursing home census pre- and post-OBRA with this data.

A second empirical concern is that it is not possible to discern how much of the change reported in the ID nursing home census from 1977 to 2004 is actual change over time, and how much of it is due to inherent differences in the data sets. The data utilized for these estimates of the ID or I/DD census are calculated from diverse data sources ranging from state-level administrative data to unrelated surveys with varying methodologies (units of analysis, target populations, survey designs, and sampling strategies). It is possible that some of the change

reported is due to the variation in the data sources rather than a reflection of actual change over time.

The third empirical concern is that these estimates do not consistently report the overall nursing home census during this time period. Thus, it is not possible to examine the population distributions of nursing home residents to determine the extent to which changes in the ID census are unique to residents with ID, or instead reflect larger trends in the overall nursing home population over the same years. While encouraging that the ID nursing home census appears to decrease, if the percentage of nursing home residents with ID (prevalence) does not decrease in tandem with the number of nursing home residents, we would conclude that the reduction in the ID nursing home census was not a unique event, but was at least partially informed by a general trend change in nursing home usage affecting all nursing home residents.

Our study addresses these empirical concerns by capitalizing on the multiple years of the cross-sectional National Nursing Home Survey (NNHS) series to provide nationally representative estimates of changes in the ID nursing home census between 1977 and 2004. This data is ideal for understanding trend change in the ID nursing home census during the OBRA enactment period since the NNHS series was fielded in years prior to and after the passage of OBRA. Addressing our first empirical concern, an indicated diagnosis of ID in the NNHS is distinct from other developmental disabilities across all years of the study, thus, a consistent measure of ID over time is provided. Addressing our second empirical concern, the NNHS employs a similar survey design and implementation strategy across the years of the survey series which reduces the possibility that any discovered change over time is due to differences in survey methodology. Addressing our third empirical concern, as the NNHS is a nationally representative sample of all nursing home patients inclusive of residents with/without ID, it

allows us the ability to analyze whether changes in the ID nursing home census over this time period is unique, or reflective of larger societal trends in nursing home usage. Therefore, we can better discern the degree to which the ID nursing home census changed during the OBRA enactment period.

It is our contention that a decline in the number of nursing home residents with ID along with simultaneous stability in the percentage (prevalence) of residents with ID in nursing homes would indicate that policy changes that occurred during the OBRA enactment period did not have a substantial effect on the ID nursing home census. In this scenario, it is likely that the decline in the ID census was not unique to nursing home residents with ID, but rather attributed to an overall decline in nursing home usage by the entire population that reduced the census of residents with/without ID evenly. Another possible scenario would be a decline in the number of nursing home residents with ID, but an increase in the percentage of residents with ID. This would indicate a decline in nursing home usage among those with/without ID that was more pronounced among those without ID, again suggesting a minimal effect of policy changes during the OBRA enactment period on the ID nursing home census. In contrast to these scenarios, what we expected to find is decline in both the number and percentage (prevalence) of nursing home residents with ID during the OBRA enactment period. This result would indicate the occurrence of an event unique to the ID nursing home population and suggest policy changes that occurred during the OBRA enactment period had a more substantial effect on the ID nursing home census.

After confirming whether and to what degree policy changes that occurred during the OBRA enactment period reduced the ID nursing home census, we turn our attention to the effectiveness of this change in eliminating “inappropriate” residential placements for persons with ID. During the pre-OBRA era, persons with ID were not offered appropriate choices for

residential living, but were instead being inappropriately placed in nursing facilities, often at ages younger than those typical for the general nursing home population (D. J. Anderson et al., 1987; Lakin et al., 1991). As a result, we expected that compared to the age distribution of the overall nursing home census, the age distribution of the ID nursing home census pre-OBRA would deviate with a higher percentage of residents at younger ages. If changes that occurred during the OBRA enactment period were indeed effective in addressing inappropriate placements, especially of younger persons with ID, we should see a shift in the age distributions among the ID nursing home census post-OBRA resulting in closer approximation to the age distribution in the overall nursing home census.

Methods

Data

We utilized data from the 1977, 1985, 1995, and 2004 National Nursing Home Survey (NNHS). Conducted by the National Center for Health Statistics (NCHS), the NNHS is a nationally representative sample of nursing home residents that employed a two-stage sampling design with the first stage providing a systematic sample of nursing home facilities in the U.S, and the second stage providing a random sample of residents within each facility. The 1977 sample included 1,451 nursing homes and 7,033 residents; the 1985 sample included 1,079 nursing homes and 5,238 residents; the 1995 sample included 1,409 nursing homes and 8,056 residents; and the 2004 survey included 1,174 nursing homes and 13,507 residents. The NNHS has not been fielded since 2004. Only data on nursing home residents were utilized for this study.

Researchers have analyzed NNHS data to provide descriptions of: the overall US nursing home population at single points in time (Bercovitz, Decker, Jones, & Remsburg, 2008; Gabrel & Jones, 2009; Hing, 1981; Jones, Dwyer, & Bercovitz, 2009); nursing home patients with

dementia (Bernstein & Remsburg, 2007); changes in the general characteristics of the nursing home population from 1985 to 1997 (Sahyoun, Pratt, Lentzner, Dey, & Robinson, 2001); and changes in nursing home expenditures from 1977-2004 (Stewart, Grabowski, & Lakdawalla, 2009). NNHS data have not been utilized to estimate changes in the ID nursing home census pre- and post-OBRA. Lakin et al. (1991) reported estimates of the number of nursing home residents with ID using the pre-OBRA NNHS survey years of 1977 and 1985, but did not have access to the NNHS surveys that were fielded post-OBRA at the time of their study. Our strategy for this study is informed by the work of Mechanic and McAlpine (2000), who utilized the 1985 and 1995 NNHS data to estimate changes in the census of nursing home residents with a mental illness pre- and post-OBRA, but did not include estimates of trend change in the ID census during this time period.

Measures and Analytic Strategy

Earlier studies by Anderson et al. (1987) and Lakin et al. (1991) utilizing the 1977 and 1985 NNHS contend that the best strategy for accurately measuring for ID in the NNHS is use of the primary diagnosis only, as opposed to using both the primary and secondary diagnosis. They provide empirical evidence of distinct differences between those with a primary or secondary diagnosis in the NNHS illustrating that a secondary diagnosis of ID may have been indicated due to cognitive limitations derived from the aging process or to developmental challenges such as mental illness occurring after the age of 18. Thus, there is a higher likelihood that those with a secondary diagnosis of ID in the NNHS did not actually have ID. We concur with their argument, which is further bolstered by the fact that the measure for secondary diagnosis of ID in the NNHS changes over time. Thus, we also question the accuracy of the secondary diagnosis of ID in the NNHS and, therefore, limit our analysis of trend change in the ID nursing home census

to those residents with a primary current diagnosis of ID. While this decision prevents us from offering estimates of the overall ID nursing home census, it does decrease the chances for error in our measurement, ensuring the validity of our analysis of trend change over time in the ID nursing home census for residents with a primary diagnosis of ID. Subsequent references to the ID nursing home census in this paper indicate the number and percentage of nursing home residents with a primary diagnosis of ID.

For the 1977 NNHS, we identified ID utilizing a binary measure that specified whether the resident had “mental retardation” indicated as the primary diagnosis at the last medical exam. For the 1985, 1995, and 2004 surveys, we identified ID using primary current diagnosis codes, which were based upon the International Classification of Diseases, 9th Revision, Clinical Modification (ICD9) (National Center for Health Statistics, 1980). Nursing home residents were identified as having ID if they had an ICD-9 primary current diagnosis code of 317, 318.0, 318.1, 318.2, or 319. As the 1977 NNHS measure for a primary diagnosis of ID likely included persons with Down syndrome (Lakin et al., 1991), for the sake of consistency of measures over time, we also coded those with an ICD-9 primary current diagnosis of 758.0 as having ID in the 1985, 1995, and 2004 data.

Age indicated the nursing home resident’s current age in years at the time of the NNHS and is grouped by age categories for analysis: 0-19, 20-29, 30-39, 40-49, 50-59, 60-69, 70-79, 80 and over.

To analyze whether there was a decline in the ID nursing home census over time and the degree to which this decline was influenced by OBRA, we estimated the total number and percentage (prevalence) of nursing home residents with ID for all years of the NNHS included in this study. We utilized STATA Version 15.0 (College Station, TX) to produce all estimates. As

the NNHS utilized a complex survey design, we used the “svy” command to adjust standard errors. All reported results were weighted to provide nationally representative estimates based upon recommendations from the NCHS. We then tested for statistical significance in changes that occurred in the ID nursing home census across survey years by calculating 95% confidence intervals. Standard errors for confidence intervals were calculated by taking the square root of the sum of squares of the standard error for each estimated statistic. Results of change in the ID nursing home census were presented for change in the ID nursing home census during the pre-OBRA period of 1977 to 1985, OBRA enactment period of 1985 to 1995, and post-OBRA period of 1995 to 2004. After comparing changes in the overall ID nursing home census, we examined trend change in the age distributions (the number and percentage of persons in successive age categories) of the ID nursing home census in order to evaluate the effectiveness of policy changes during the OBRA enactment period on reducing inappropriate nursing home placements for persons with ID.

Results

Estimates of the ID nursing home census for all years of the NNHS utilized in the study are reported in Table 1. As a point of comparison, the census for all nursing home residents grew over the years of the study, with marked increases from 1,303,126 in 1977 to 1,489,508 in 1985 and 1,548,594 in 1995, then a slight decrease to 1,492,207 in 2004.

The trend in the ID nursing home census for this same time period was starkly different from the overall nursing home census. In the pre-OBRA years of 1977 to 1985, there was a moderate decrease in the number and percentage of nursing home residents with a primary diagnosis of ID from 42,424 (3.26%) in 1977 to 37,804 (2.54%) in 1985. The decrease in the percentage was statistically significant, 95% CI [-1.40, -0.04], but the change in the number of

residents, 95% CI [-14,135, 4,895], was not. In comparison, the most dramatic change occurred in the ID nursing home census during the OBRA enactment period of 1985 to 1995. During this time period, the number and percentage of nursing home residents with a primary diagnosis of ID decreased severely from 37,804 (2.54%) in 1985 to 14,367 (0.87%) in 1995. Changes in both number, 95% CI [-31,179, -15,694], and percentage, 95% CI [-2.18, -1.15], were statistically significant. In contrast to the severe decline in the ID nursing home census from 1985 to 1995, change in the ID nursing home census was negligible during the post-OBRA period of 1995 to 2004. The number and percentage of nursing home residents with a primary diagnosis of ID decreased from 14,367 (0.87%) in 1995 to 12,581 (0.84%) in 2004. Neither the change in number, 95% CI [-6,013, 2,442], nor percentage, 95% CI [-0.31, 0.24], was statistically significant.

-Table 1 about here-

Overall trend change in the number and percentage of the ID nursing home census illustrates the degree to which the OBRA enactment period influenced the reduction in the ID nursing home census over the time period of the study. From 1977 to 2004, the number of nursing home residents with ID decreased by 70.3%. Highlighting the effect of policy changes on this drastic reduction, the majority of the decrease in the number of nursing home residents with ID occurred during the OBRA enactment period of 1985 to 1995, during which there was a 62% decrease in the number of nursing home residents with ID. A similar trend was apparent in the percentage (prevalence) of nursing home residents with ID. From 1977 to 2004, the prevalence decreased by 74.2%. Again, the majority of this change was during the OBRA enactment period of 1985 to 1995, during which the prevalence decreased by 65.7%. The slightly higher reduction in percentage (prevalence) than number of nursing home residents with ID is

informed by growth in the overall nursing home population during this same time period - 12.7% growth in the overall nursing home population for all years of the study, from 1977 to 2004; and 3.8% growth during the OBRA enactment period from 1985 to 1995. Overall, the parallel steep decline in number and percentage of nursing home residents with ID provides confirmation of the uniqueness of the seismic reduction in the ID nursing home census during this time period.

Having confirmed the unique effect of changes that occurred during the OBRA enactment period on the ID nursing home census, we now turn our attention to whether the decline in the ID nursing home census reflected a reduction in inappropriate placements by analyzing trend change in the age distribution of the ID nursing home census. Changes in number and percentage of the ID nursing home census by age group are presented in Table 2. Changes in the overall nursing home census are also reported as a point of comparison. The effect of the OBRA enactment period on the ID nursing home census was consistent among those ages 20-69. For all nursing home residents with ID in these age groups, pre-OBRA change varied, but was either negligible, moderate, or inconsistent in influencing the direction or degree of change between number and percentage. In contrast, during the OBRA enactment period, change among those ages 20-69 was reflected in a parallel severe decrease in number and percentage. Post-OBRA, change for all of these age groups was negligible.

-Table 2 about here-

The outliers among nursing home residents with ID were among the 0-19, 70-79 and 80+ age groups. In the 0-19 age group, the number and percentage of nursing home residents severely decreased between 1977 and 1985, then showed minimal change through 2004. Among the 70-79 age group, the OBRA enactment period of 1985 to 1995 was associated with a decrease in number of residents, but an increase in percentage of residents. This was due to the fact that the

decrease in number of residents at younger ages outpaced the decrease among those aged 70-79 during this time period. This resulted in an increase in the percentage of nursing home residents with ID in this age category. Among those ages 80 and over, the ID nursing home census increased in both number and percentage during the OBRA enactment period of 1985 to 1995. The numerical increase was slight; however, due to the severe decrease in number of residents ages 20-69, the percentage of nursing home residents with ID ages 80 and over increased dramatically.

Comparison with age group trends in the overall nursing home census during the same time period further confirm that changes in the ID nursing home census were unique. Similar to those with ID, there were distinct decreases in number and percentage of all nursing home residents ages 20-69 from 1985 to 1995. Some of this change is accounted for by changes in the ID nursing home census, with the remainder likely informed by reductions in the nursing home census among other groups covered by OBRA policy, such as those with mental illness (Mechanic & McAlpine, 2000). What is distinctly different from the ID census is that there is a rebound in the overall nursing home census from 1995 to 2004 in those ages 40-69. Thus, post-OBRA, the overall nursing home census for those ages 40-69 grew. Yet, emphasizing the continued effectiveness of policy changes in reducing inappropriate nursing home placements for persons with ID, this increase did not include those with a primary diagnosis of ID. Similar to the ID nursing home census, there is also an increase in the overall nursing home census for those ages 80 and over during the OBRA enactment period of 1985 to 1995. Distinct from the ID nursing home census, the overall nursing home census shows growth in the 0-19 age group from 1995 to 2004, and a decrease in the 70-79 age group from 1985 to 2004.

Figure 1 provides a visual representation of trend change in the age distribution of the nursing home census for residents with ID (left bars) and for all nursing home residents (right bars). As expected, the age distribution of the ID nursing home census pre-OBRA deviated severely from the age distribution of the overall nursing home census. While the overall nursing home census was top-heavy, with the majority of residents ages 70 and over (over 80% in both years), the ID nursing home census in these years was middle-heavy, with the majority of nursing home residents with ID ages 30-69 (over 74% in both years).

-Figure 1 about here-

Post-OBRA, the age distribution of the overall nursing home census shows signs of an aging trend in the nursing home population, with a slight decrease in the percentage of residents ages 70-79 and a slight increase in the percentage of residents in the 80 and over age group. Empirical evidence of the effectiveness of changes that occurred during the OBRA enactment period on reducing inappropriate placements of younger persons with ID in nursing homes suggests changes in the ID nursing home census post-OBRA are more stark. Instead of a gradual pattern of population aging as we see in the overall nursing home census, there is a dramatic shift among nursing home residents with ID. Post-OBRA, the majority of nursing home residents with ID are no longer in the 30-69 age range, but are now in the 50-80+ age range (over 76% in both years). While still markedly dissimilar from the overall nursing home age distributions, the post-OBRA age distribution for the ID nursing home census more closely approximates the shape of the overall nursing home age distribution that it did pre-OBRA.

Discussion

The Omnibus Budget Reconciliation Act (OBRA) of 1987 was intended to reduce the number of inappropriate residential placements of persons with intellectual disability (ID) in

nursing homes., We estimate changes in the population of U.S. nursing home residents pre- and post-OBRA utilizing the nationally representative 1977, 1985, 1995, and 2004 National Nursing Home Surveys. As expected, the ID nursing home census decreased dramatically from 1977 to 2004. The concurrent decline in the ID nursing home census in both number and percentage at a time when the population of nursing home residents without ID grew suggests that changes in the ID nursing home census are not attributable to larger trends in nursing home usage in the overall population. Instead, the trend decline in the ID nursing home census in the NNHS suggests that policy changes that occurred during the OBRA enactment period were successful in reducing the ID nursing home census particularly during the 1985 to 1995 time period.

Changes in the age distribution of the ID nursing home census provide evidence that policy changes implemented during the OBRA enactment period were effective in reducing inappropriate placements of younger adults with ID in nursing homes. Pre-OBRA, the age distribution for the ID nursing home census was starkly different from the age distribution for the overall nursing home census, with a much higher percentage of residents with ID in the 30 to 69 age range. Although remaining distinctly different from the age distribution for the overall nursing home census, we did find evidence that the age distribution for the ID nursing home census post-OBRA more closely approximated trends in the overall nursing home population. Post-OBRA, the majority of nursing home residents with ID were in the 50 to 80 and over age range. Together, the results from this study provide empirical evidence that legislative and policy changes that occurred during the OBRA enactment period were effective in severely reducing the ID nursing home census, as well as reducing inappropriate placements of younger adults with ID in nursing homes.

The primary limitations to our study regard the data. The first limitation is that we were not able to provide estimates of the overall ID nursing home census due to changes in the measures for secondary diagnosis of ID in the NNHS. Thus, our estimates only reflect trend change in the number and percentage of nursing home residents with a primary diagnosis of ID. Although this decision does insure the accuracy of our estimates of trend change, we could not provide accurate estimates of trend change in the overall ID nursing home population.

The second limitation is that we were not able to stratify analysis by state. There is evidence that the implementation of required Preadmission Screening and Resident Review (PASARR) required by OBRA was uneven across states, resulting in variation in the timing of the reduction of the ID nursing home census by state (Scott et al., 2009). This was at least partially informed by the slow development of viable community residential placements for persons with ID in some states due to budgetary priorities and constraints (Braddock et al., 1990). We were not able to analyze whether the reduction in the ID nursing home census observed varied by state because the NNHS does not provide information on where facilities and residents were located.

The third limitation is that we could not provide estimates past 2004. Improvements in the regulations of OBRA within the past 20 years have been facilitated by programs such as the Money Follows the Person (MFP) grant program. Implemented by Congress in 2005, MFP introduced flexibility into Medicaid and Medicare funding allowing funds formerly utilized to provide institutional care for a person with disability to “follow” the person into appropriate community residential settings (Scott et al., 2009). The improvement of community services for persons with ID, coupled with the effect of ongoing OBRA regulation requirements, were expected to result in a continued reduction of the ID nursing home census over time (Braddock et

al., 1990). We would have liked to determine the degree to which the ID nursing home census continued to gradually decline post 2004, and whether the age distribution of the ID nursing home census continued to steer toward a closer approximation that of the overall nursing home population.

Unfortunately, the NNHS was not fielded after 2004 since it was folded into the National Study of Long-Term Care Providers (NSLTCP) in 2012. The NSLTCP does not include individual-level data on nursing home residents, such as the primary diagnosis or age of each individual nursing home resident, but rather provides aggregate data reported by nursing homes in the study. Additionally, the NSLTCP measure for developmental disability combines nursing home residents with ID, autism, and Down syndrome into one category. Furthermore, the NSLTCP does not include individual measures for each disability category and does not delimit whether a disability diagnosis is a primary or secondary condition. Thus, it was not possible to extend our analysis beyond 2004. However, as OBRA was signed into law in 1987, the date range of this study does allow us to capture the historic changes that occurred in the time period immediately following this legislation.

There may be possibilities for garnering data on the ID nursing home population post-OBRA in other data sets. Though not useful for comparing the pre- and post-OBRA census as in this study, information on the ID nursing home census from 1988 on is contained in the Centers for Medicare and Medicaid Minimum Data Set (CMS MDS) (Buchanan, Wang, & Ju, 2002; Phillips & Morris, 1997; Polister, Lakin, Smith, Prouty, & Smith, 2002). Braddock and colleagues collected data on the ID nursing home population directly from state I/DD agencies, as well as from the Online Survey Certification and Reporting (OSCAR) System of CMS (Braddock et al., 2015). In addition, though not matured to the point of topical analysis of the ID

nursing home census, it may be possible to eventually link private or public service data to the Transformed Medicaid Statistical Information System (T-MSIS) that was introduced in 2010. This data may allow analysis of trend change in the ID nursing home population, as well as more detailed information on state and federal services and spending on this population (Baugh, Ireys, Irvin, & Appold, 2017).

Despite data limitations, this study was able to capitalize on the data from the 1977, 1985, 1995, and 2004 NNHS to analyze trend change in the ID nursing home census during this time period. While disparate studies provide initial evidence of a stark reduction in the ID nursing home census during the OBRA enactment period (D. J. Anderson et al., 1987; Braddock, 1999; Braddock et al., 1989, 1990; Braddock et al., 2005, 2017; Lakin et al., 1991; Scott et al., 2009; Sirrocco, 1987), they were not intended or able to provide empirical evidence of trend change over the time during the pre-OBRA, OBRA enactment period, and post-OBRA period due to inconsistencies in survey populations and methodologies. Our study addresses these concerns and provides empirical evidence that legislative and policy changes that occurred during the OBRA enactment period were effective in severely decreasing the ID nursing home census as well as reducing inappropriate placements of younger adults with ID in nursing homes. As data becomes available, follow-up studies should explore the extent to which these trend changes continued past 2004.

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Table 1: Nursing home census, National Nursing Home Survey 1977, 1985, 1995, 2004

		1977	1985	1995	2004
Intellectual disability	N	42,424	37,804	14,367	12,581
	(SE)	(3,264)	(3,594)	(1,640)	(1,400)
	%	3.26	2.54	0.87	0.84
	(SE)	(.25)	(.24)	(.10)	(.09)
All nursing home residents	N	1,303,126	1,489,508	1,548,594	1,492,207

Note: SE=Standard error

Figure 1: Nursing home census age distributions - National Nursing Home Survey 1977, 1985, 1995, 2004

