

Research

The Influence of Residence Type on
Personal Outcomes

 **CQL**SM | The Council on
Quality and Leadership
www.c-q-l.org

Running head: RESIDENCE TYPE AND OUTCOMES

The Influence of Residence Type on Personal Outcomes

Carli Friedman

Corresponding author:

Carli Friedman, PhD

Email: cfriedman@thecouncil.org

CQL | The Council on Quality and Leadership

100 West Road, Suite 300

Towson, MD, 21204, USA

Acknowledgements:

Thank you to Mary Kay Rizzolo for reviewing this manuscript and providing feedback.

Reference:

Friedman, C. (2019). The influence of residence type on personal outcomes. *Intellectual and Developmental Disabilities*, 57(2), 112-126. <https://doi.org/10.1352/1934-9556-57.2.112>

Abstract

Over the last five decades, the state institution census has decreased 85% in the United States. Despite these radical shifts away from institutionalization, people with intellectual and developmental disabilities (IDD) continue to struggle to be meaningfully included in the community. For these reasons, the aim of this study was to explore if and how residence type impacts attainment of quality of life outcomes of people with IDD in the United States. To do so, we analyzed Personal Outcome Measures[®] interviews from approximately 1,350 people with IDD. Findings suggest much of what has historically been considered deinstitutionalization of people with IDD is transinstitutionalization, particularly with provider owned or operated settings. A systemic overhaul is needed to create an effective community infrastructure.

Keywords: Deinstitutionalization; transinstitutionalization; provider owned or operated homes; quality of life

The Influence of Residence Type on Personal Outcomes

The United States census of state institutions for people with intellectual and developmental disabilities (IDD) peaked in 1967, with the majority of people with IDD moving to community based settings, such as group homes (Braddock et al., 2015). Over the last five decades, the state institution census decreased 85%, an average of 4% per year (Braddock et al., 2015; Braddock, Hemp, Tanis, Wu, & Haffer, 2017). A number of factors have contributed to the large decline of congregate settings and move toward smaller community-based residential settings.

The Path to Deinstitutionalization

Early constructions of intellectual and developmental disabilities (IDD), then referred to as “feebleminded” or “idiocy,” related to “a failure of the will” (Trent, 1994, p. 16); as such, the United States developed institutions to educate people with IDD so they could become ‘productive’ members of society. However, as institutions expanded, these spaces shifted from educational schools to custodial institutions (Carlson, 2010; Trent, 1994). This was because large numbers of people in larger spaces were harder to teach and instead were managed, and because of an economic downturn that favored hiring able-bodied workers in the community rather than educated people with IDD (Carlson, 2010; Trent, 1994). As a result, these institutional settings modeled themselves after asylums for people with psychiatric disabilities and functioned as locations of care and medical practices instead of focusing on education (Carlson, 2010; Trent, 1994).

Meanwhile, the civil war helped shift IDD to state burden and responsibility. Families that were previously paying institutions privately had less cash because of post war inflation (Trent, 1994). As a result, there was a growth in public funding leading to state appointed boards

(Trent, 1994). These new state run boards recognized distinct classes of IDD, created new policies of custody, and arranged new cottage/colony institution plans accordingly (Trent, 1994). As facilities expanded attempts to stretch funding to larger operations lead to new visions of productivity. Institutions' goals thereby shifted from "an academic enterprise" to a "vocational one" in order to make the institution productive by putting those people with higher abilities to work (Carlson, 2010; Trent, 1994, p. 83).

The period of the 1890s to 1920s marked another large change in IDD constructions, and as a result, institutions. Science, rather than "sentimental goodwill or public paternalism" (Trent, 1994, p. 137), became the new method for social change because of interests in heredity, new developments in IQ testing, popular social Darwinism, and trends in eugenics. As a result, sterilization served as a method of eugenics, and also helped with the ever-increasing institution population rates because experts believed that sterilized people could be safe in communities (Trent, 1994). As a result, sterilization allowed for people with IDD to be 'paroled' wherein superintendents approved people to move back to the community after a stop in a smaller institutional colony (Trent, 1994). Although the move back to the community was a positive step, 'paroling' itself served to criminalize impairments. People had to prove a certain degree of normalcy to be 'pardoned' for having an impairment.

The rise of the confessional parent genre in the 1950s started a new trend of disability as parent tragedy while at the same time portrayed people with IDD as special and angelic (Trent, 1994). Although institutionalization was still common, having a child with IDD was no longer seen as related to an immoral family heredity (Carlson, 2010; Trent, 1994). According to Trent (1994), "retarded children could be helped; people need not fear retarded children; with proper

education and support, may retarded children could develop their potential; and by implication, having a retarded child was nothing to be ashamed of” (p. 241).

John F. Kennedy’s Panel on Intellectual and Developmental Disabilities in 1961 marked another large shift in how IDD was understood; IDD became a “*health and human development* problem, one that could be tackled scientifically” (emphasis original; Trent, 1994, p. 249). President Kennedy’s panel strongly advocated for downsizing institutions and expanding community alternatives (Braddock, 2007). Important legal rulings such as *Wyatt v. Stickney* also resulted in sweeping reforms of state facilities and set standards of care. Later litigation such as *Olmstead v. LC*, which reinforces people with disabilities’ rights to be in the community, has also spurred class action litigation that plays a pivotal role in promoting community living.

Changes to long term services and supports (LTSS) – services and supports which help people with activities of daily living and instrumental activities of daily living over an extended period, rather than acute care – have also contributed to a decreased institutional census. For example, the United States authorized the Medicaid Home and Community Based Services (HCBS) waiver program in 1981 as an alternative to intermediate care facilities for individuals with developmental disabilities (ICFDD). HCBS waivers allow states to ‘waive’ key provisions of the Social Security Act (i.e., statewideness, comparability of services, and income and resource rules) to create and expand community LTSS particularly tailored to populations that would typically require institutional care. Surpassing ICFDD funding in 2000, Medicaid HCBS waivers are now the largest funders of LTSS in the United States (Braddock et al., 2017).

Throughout history, advocacy by people with IDD and family members has also demanded institutional reform and community alternatives. The ‘popularity’ of discrimination and neglect among the media in the 1950s and 1960s, such as the Willowbrook State School

exposé (Braddock, 2007), as well as the ever-growing self-advocacy movement, have helped encourage this advocacy. Finally, another reason for these shifts to community-based settings is because of the benefits to and preferences of people with IDD. Compared to institutional settings, people in the community have increased self-determination, larger social networks, increased participation in community life, and increased choice (Beadle-Brown et al., 2016; Larson, Lakin, & Hill, 2013).

Modern Community Living

Despite these radical shifts in institutionalization, people with IDD still struggle to be meaningfully included in and engaged with the community, in large part because of a lack of community infrastructure (Cullen et al., 1995; Forrester-Jones et al., 2002; Ligas Consent Decree Monitor, 2016, 2017). People with IDD with more severe impairments in particular often face service disparities, and as a result are less likely to have equal opportunities compared to those people with IDD with less severe disabilities. Historically, people with more severe impairments have been institutionalized at higher rates than those with less complex disabilities (Lulinski-Norris, 2014). They are not only more likely to live in institutions, in the community people with severe impairments are also less likely to own their own homes than people with low support needs (Hall et al., 2005). Research also suggest people with severe impairments have fewer day-to-day experiences – they have less to do on a daily basis (Felce, 1997).

In recognition of some of the shortcomings of LTSS in regard to community integration, the Centers for Medicare and Medicaid Services (CMS) implemented the Medicaid HCBS final settings rule (CMS 2249-F/2296-F) in 2014 (Centers for Medicare and Medicaid Services, 2014b). The settings rule is an attempt to shift

away from defining home and community-based settings by ‘what they are not,’ and toward defining them by the nature and quality of participants’ experiences... [to] establish a more outcome-oriented definition of home and community-based settings, rather than one based solely on a setting’s location, geography, or physical characteristics. (Centers for Medicare and Medicaid Services, 2014a, p. 2)

The rule’s emphasis on person-centered planning also shift how many states must provide their services, such as away from segregated day services.

As a result of the significant shift away from institutions and traditional congregate care, as well as the continued lack of community integration of people with IDD, the aim of this study was to explore if and how residence type continues to impact the quality of life outcomes of people with IDD in the United States. In doing so, our research question was: are there differences in residence types and impairment severity that influence attainment of personal outcomes of people with IDD? We explored this question by analyzing Personal Outcome Measures[®] interviews from approximately 1,350 people with IDD.

Methods

Participants

We received the secondary survey data with no identifiers; as such our institutional research board (IRB) determined it was exempt from full review. Data were originally collected over a two-year period (January 2015 to January 2017) from hundreds of organizations, including local, county, and state governments, that provide any type of the following services to people with IDD: service coordination; case management; family and individual supports; behavioral health care; employment and other work services; residential services; non-traditional

supports (micro-boards and co-ops); and, human service systems. Data were collected from 1,341 people with IDD (Table 1). While age and gender were relatively evenly distributed across demographic categories, the majority of participants were White ($n = 998$, 74.4%), and used verbal/spoken language as their primary communication method ($n = 1102$, 82.2%).

Participants lived in the following residence types: own homes/apartments; family homes; host family/family foster care; provider owned/operated home; state-operated HCBS group home; state-operated ICFDD; private ICFDD; assisted living facility; nursing home; transitional housing; homeless; and, other. We combined the categories of state-operated ICFDD and private ICFDD due to a limited number of participants in each setting in the sample. Moreover, we also combined the categories of host family/family foster care, assisted living facility, nursing home, transitional housing, and homeless with the 'other' category due to a limited number of people with IDD in our sample in these settings (Table 2). In terms of residence type, the majority of participants ($n = 667$, 50.5%) lived in provider owned or operated homes, their own homes ($n = 284$, 21.2%), or family homes ($n = 213$, 15.9%). The remaining participants lived in ICFDD ($n = 47$, 3.5%), state-operated HCBS group homes ($n = 43$, 3.2%), and other settings ($n = 51$, 3.8%) (Table 1).

Since the data did not include clinical information, as a proxy for impairment level, we considered those with complex medical support needs or comprehensive behavioral support needs to have more severe impairments. The data defined complex medical support needs as those people who needed skilled nursing care twelve or more hours per day. The data defined comprehensive behavioral support needs as those people that required twenty-four hour supervision particularly due to risk of dangerous behavior, such as harm to themselves or others.

The proxy item was dichotomous (severe impairments (1); less severe (0)). 27.6% of the participants ($n = 370$) had severe impairments (Table 1).

Measure

The instrument used in this study was the Personal Outcome Measures[®] (The Council on Quality and Leadership, 2017b), developed by the international non-profit disability organization the Council on Quality and Leadership (CQL). CQL designed the Personal Outcome Measures[®] to determine people with disabilities' quality of life, including self-determination, choice, self-advocacy, and supports, in a person-centered manner. The Personal Outcome Measures[®] includes 21 indicators divided into five factors: My Human Security; My Community; My Relationships; My Choices; and, My Goals (Table 3).

For every participant, the Personal Outcome Measures[®] administration occurs in three stages. In the first stage, a trained Personal Outcome Measures[®] interviewer has an in-depth conversation(s) with the participant with disabilities about each of the indicators (approximately one to two hours). For these conversations, the interviewer follows specific open-ended prompts. During the second stage of the Personal Outcome Measures[®] interview, the interviewer speaks with someone who knows the participant with disabilities best, and knows about organizational supports, such as a case manager or direct support professional, and asks them questions about individualized supports and outcomes to fill in any gaps (approximately one to two hours). During the final stage, the interviewer observes the participant in various settings if necessary, and then completes the indicator questions about personal outcomes and individualized supports based on the information gathered in first two stages. Individual record reviews are also conducted as needed. As the measure is person-centered, if there are any discrepancies across stages, the person with IDD's answers are the ones used.

CQL developed the Personal Outcome Measures[®] over 25 years ago based on findings from focus groups with people with disabilities, their family members, and other key stakeholders about *what really mattered* in their lives. The Personal Outcome Measures[®] has been continuously refined over the past two decades through pilot testing, 25 years of administration, commission of research and content experts, a Delphi survey, and feedback from advisory groups (The Council on Quality and Leadership, 2017b). The Personal Outcome Measures[®] has construct validity (Friedman, 2017c), and reliability, as all interviewers need to pass reliability tests with at least 85% agreement before being certified (The Council on Quality and Leadership, 2017a).

Variables and Analysis

We analyzed the data to examine the following research question: are there differences in residence types and impairment severity that influence attainment of personal outcomes of people with IDD? Because the five Personal Outcome Measures[®] factors (Table 3) represent different areas of quality of life, we used the five factor scores as the dependent variables (DVs) for this study, rather than a total instrument score because the total score may not be as informative as the separate factors. Scores for each of these factors were equal to the total number of outcomes present for each factor (i.e., Human Security = 7; Community = 4; Relationship = 5; Choices = 3; and, Goals = 2).

The independent variable (IV) was the residence type of the participants: own homes/apartments; family homes; provider owned/operated home; state-operated HCBS group home; ICFDD; and, other. Because people with severe impairments can have poorer outcomes, it was also important to both examine interactions with impairment severity to determine if personal outcomes differ depending on severity, and to control for impairment level to examine

across people with IDD. For these reasons, we also used impairment severity of participants (see demographics) as an IV.

Data were first analyzed using descriptive statistics. Then to explore the research question, we conducted a multivariate analysis of variance (MANOVA) to determine significant differences between the six residence types (i.e., own homes/apartments; family homes; provider owned/operated home; state-operated HCBS group home; ICFDD; other) on the five quality of life factors (DVs) – My Human Security, My Community, My Relationships, My Choices, and My Goals. We utilized Pillai's Trace instead of Wilks' Lambda because of unequal cell size and failed homogeneity of variance-covariance. Following the MANOVA, we conducted analyses of variance (ANOVAs) for each of the DVs as follow-up tests. Finally, we conducted post hoc analyses using Tukey's HSD to compare residence types on the univariate ANOVAs for each significant factor.

Results

Participants had an average Human Security score of 3.82 ($SD = 1.74$) out of a possible 7 indicators (54.6% of outcomes present). Participants had an average Community score of 2.22 ($SD = 1.39$) out of a possible 4 indicators (55.5% of outcomes present). Participants had an average Relationship score of 2.28 ($SD = 1.59$) out of a possible 5 indicators (45.6% of outcomes present). Participants had an average Choices score of .87 ($SD = 1.03$) out of a possible 3 indicators (29.0% of outcomes present). Participants had an average Goals score of 1.01 ($SD = .80$) out of a possible 2 indicators (50.5% of outcomes present). However, scores on the five factors varied by residence type and impairment severity (Table 4).

We conducted a 2 x 6 MANOVA to determine the effect of impairment level and residence type on the five factor outcomes (DVs). There was not a significant main effect for

impairment severity, $F(5, 1222) = .47, p = .80$, Pillai's trace = .002, partial $\eta^2 = .002$, but there was a significant main effect for residence type, $F(25, 6130) = 7.50, p < .001$, Pillai's trace = 0.15, partial $\eta^2 = .030$. There was also a significant interaction effect, $F(25, 6130) = 1.93, p = .004$, Pillai's trace = .039, partial $\eta^2 = .008$.

We conducted ANOVAs of the interaction (residence type X impairment level) on the DVs as a follow up test for the MANOVA using the Bonferroni method (.01). The following ANOVAs were significant with the interaction term: My Relationships, $F(5, 1226) = 3.98, p = .001$, partial $\eta^2 = .016$; and, My Choices, $F(5, 1226) = 5.02, p < .001$, partial $\eta^2 = .020$. We calculated post hoc analyses for the interaction term on My Relationships and My Choices using pairwise comparisons using Sidak correction (Figure 1). People with severe impairments living in their own homes scored significantly lower on Relationships than those in family homes ($p < .001$). People with less severe impairments living in family homes scored significantly higher on Relationships than those in provider homes ($p < .001$) and ICFDD ($p = .011$). Those with severe impairments in family homes scored significantly higher on Relationships than provider homes ($p < .001$).

People with less severe impairments living in their own homes scored significantly higher on Choices than those in family homes ($p < .001$), provider homes ($p < .001$), ICFDD ($p = .008$), and 'other' settings ($p < .009$); however, people with severe impairments living in their own homes did not score significantly different on Choices than any other residential settings. People with severe impairments living in family homes scored significantly higher on Choices than those in provider homes ($p = .005$), state-operated HCBS group homes ($p = .044$), and ICFDD ($p = .017$).

We also conducted ANOVAs on the dependent variables as follow up tests to the MANOVA for the significant main effects for residence type. Using the Bonferroni method, we tested each ANOVA at the .01 level. The following ANOVAs were significant with residence type: My Human Security, $F(5, 1226) = 5.57, p < .001$, partial $\eta^2 = .022$; and My Community, $F(5, 1226) = 19.45, p < .001$, partial $\eta^2 = .073$; My Relationships, $F(5, 1226) = 8.46, p < .001$, partial $\eta^2 = .033$; and, My Choices, $F(5, 1226) = 6.46, p < .001$, partial $\eta^2 = .026$. We calculated post hoc analyses to the univariate ANOVAs for each factor using pairwise comparisons at the .0017 level (Bonferroni correction). Controlling for impairment level, people with IDD living with their family scored significantly higher on Human Security than those in provider homes ($p < .001$) (Figure 2). Controlling for impairment level, people living in their own homes scored significantly higher on Community than those in provider homes ($p < .001$), state operated HCBS group homes ($p < .001$), or ICFDD ($p < .001$). Controlling for impairment level, people living in family homes scored significantly higher on Community than those in provider homes ($p < .001$), state operated HCBS group homes ($p < .001$), or ICFDD ($p < .001$). Controlling for impairment level, people living in ‘other’ settings scored significantly higher on Community than those in ICFDD ($p = .001$). Controlling for impairment level, people living in family homes scored significantly higher on Relationships than those in provider homes ($p < .001$). Controlling for impairment level, people living in their own homes scored significantly higher on Choices than provider homes ($p < .001$), and ICFDD ($p < .001$).

Discussion

While the institutionalization of people with IDD is at an all-time low, people with IDD still fail to be *meaningfully* included in, and engaged with, the community. In fact, instead of community integration, many people with IDD have merely become physically relocated into the

community (Cullen et al., 1995; Forrester-Jones et al., 2002; Ligas Consent Decree Monitor, 2016, 2017). The aim of this study was to explore the impact of residential type and impairment severity on people with IDD's attainment of personal outcomes.

Our findings revealed a lack of significant differences between ICFDD and provider owned or operated homes, reflecting “transinstitutionalization.” Transinstitutionalization refers to the move from one institutional setting to another type of institution, such as a nursing home (Blair & Espinoza, 2015; O'Mahony, 2013; Prins, 2011; Sisti, Segal, & Emanuel, 2015; Wachtler & Bagala, 2013). Transinstitutionalization is typically discussed in the context of people with psychiatric disabilities who have largely shifted from large state institutions to nursing homes, jails and prisons, and homelessness (Clifford, 2006; O'Mahony, 2013; Prins, 2011; Sisti et al., 2015; Wachtler & Bagala, 2013). Research suggests transinstitutionalization of people with psychiatric disabilities is not related to population increases, changes in employment rates, or changes in poverty rates (Prins, 2011). While changes in Medicaid led to deinstitutionalization in the United States, and Medicaid remains “one of the most important components of the health care safety net” for people with psychiatric disabilities (Frank, Goldman, & Hogan, 2003, p. 101), these same systems, which coincide with a lack of community-based infrastructure, produce transinstitutionalization (Blair & Espinoza, 2015; Prins, 2011).

Despite being relatively common for institutionalized people with psychiatric disabilities, there is very little research about transinstitutionalization of people with IDD. One of the few articles about transinstitutionalization of people with IDD, Spagnuolo (2016), argues, “the legacy of institutionalization and congregate care has shaped current residential services, meaning that ‘services today have become standardized, inflexible and unaccountable to those they serve’” (n.p.). Spagnuolo (2016) differentiates between two types of transinstitutionalization of people

with IDD – overt and less overt. In overt transinstitutionalization, much like with people with psychiatric disabilities, people with IDD are confined in medical institutions, such as hospitals (Spagnuolo, 2016). Less overt transinstitutionalization on the other hand are shifts to those settings which are “institutions without walls,” most often group homes (Spagnuolo, 2016, n.p.). Spagnuolo (2016) argues that these settings frequently hold the same prejudicial assumptions as institutions about the dependency and abilities of people with IDD, and do not respect the rights of people with IDD. Moreover, Spagnuolo (2016) suggests the general lack of real community housing choices is also evidence of transinstitutionalization of people with IDD.

Our findings suggest evidence for the modern transinstitutionalization of people with IDD. In our sample of approximately 1,350 participants, people with IDD did not have significantly better outcomes in provider owned or operated settings compared to ICFDD in terms of any area of quality of life – human security, community, relationships, choices, or goals. This was true both when impairment level was controlled and when we explored interaction with impairment level. Because of systems, pervasive attitudes and paternalistic views, and a lack of strong community infrastructure there has been a shift from the confines of one setting (state institutions) to another (provider owned or operated settings).

We in no way mean to suggest people with IDD should return to institutions, or that the lack of significant findings between ICFDD and provider settings means institutions are favorable settings; indeed, this runs counter to decades of evidence that people with IDD excel in and prefer community based settings (Hemp, Braddock, & King, 2014; Larson et al., 2013; Mansell & Beadle-Brown, 2004). As such, we believe it is not necessarily that ICFDD are doing well, as it is that other settings, such as group homes, are negatively impacted by poor

community infrastructures, rights violations, a lack of continuity and security (e.g., direct support turnover issues), and negative disability attitudes.

Because of these disparities, and because there is still a need for increased quality of life, we believe our findings should serve as an impetus to push provider owned or operated settings to be more progressive. In fact, according to our findings, people with IDD in provider homes are less likely to have community, relationship, and choice outcomes compared to people in a number of other settings, such as individual or family homes. For true social inclusion, there must be a complex combination of equitable access and quality, “wherein success is measured through self-determination and empowerment... [and] access in this instance is about social capital” (Friedman, 2017a, p. 5; Gidley, Hampson, Wheeler, & Bereded-Samuel, 2010).

We recognize providers often operate in a limited fiscal landscape and face significant challenges due to immense staff turnover (American Network of Community Options and Resources, 2014; Hewitt, 2014); however, abolishing transinstitutionalization requires provider transformation that shifts the culture of the organization by moving beyond compliance and custodial models of care, reexamining norms and removing assumptions, introducing evidenced based person-centered practices, and being accountable to the people with IDD they support. Appreciative inquiry, which builds off what organizations are doing well, may be a useful methodology to begin this change (Cooperrider, Peter Jr, Whitney, & Yaeger, 2000; Cooperrider & Srivastva, 1987).

However, organizational transformation is not enough, particularly given the lack of community infrastructure, and gaps in service provision. As states look to transform their LTSS systems, we recommend they look to individual and family homes which, according to our findings, continue to be the gold standard in terms of quality of life outcomes. Across

impairment severity, people with IDD living in their own homes or family homes had some of the highest human security, community, relationships, and choices outcomes. For people with severe impairments in particular, family homes may result in significantly better relationship and choices outcomes, even compared to people who live in their own homes. States should consider these settings both in terms of expanding provision in them, and determining features that make these settings successful so that states can replicate these features in other settings (e.g., shared living settings).

While states should look to the features of these types of settings as they restructure service provision, it is critical they remember family members already face an increased burden, and the United States LTSS system is built largely upon unpaid informal labor (Gallanis & Gittler, 2012; Rizzolo, Hemp, Braddock, & Schindler, 2009). Thus, as states work to come into compliance with the HCBS Settings Rule, and aim to reduce their institutional biases, family support is crucial, especially as caregivers age. One such small change that would not result in increased expenditures is states paying family members for providing personal care services (e.g., Friedman & Rizzolo, 2016). As community based settings are also significantly more cost effective than institutions (Braddock et al., 2017), states can use the financial surplus that comes with deinstitutionalization to expand LTSS provision to reduce disparities and large waiting lists (Larson et al., 2016), as well as expand those services that support families, such as respite and family support services (Friedman, 2017b; Friedman, Lulinski, & Rizzolo, 2015).

Ending transinstitutionalization also requires dismantling Medicaid's institutional biases (Blair & Espinoza, 2015; Ligas Consent Decree Monitor, 2016, 2017). While alternative funding mechanisms, such as HCBS waivers, exist, they "do not eliminate states' obligations to pay for services provided in the isolation of institutions... In Medicaid, integration is optional, but

segregation is mandatory” (Crossley, 2017, p. 5). The Medicaid HCBS Settings Rule is one step in the right direction as it recognizes “innovative strategies” must be “develop[ed] and implement[ed] to increase opportunities for Americans with disabilities and older adults to enjoy meaningful community living” (Centers for Medicare and Medicaid Services, 2014a, n.p.).

Although the HCBS Settings Rule emphasizes a shift to person-centered planning, the rule does not include oversight mechanisms or increased funding to ensure consistent compliance. This may be particularly problematic as we found no significant differences in achievement of goal outcomes across residence types. Moreover, regardless of residential setting, less than half of the participants were working on goals they chose. People with IDD are often denied the opportunity to choose their goals, which is one of the main reasons the HCBS Settings Rule places so much emphasis on person-centered planning (Centers for Medicare and Medicaid Services, 2014b). Thus, improvements in quality of life of people with IDD depend not only on changes made by providers or states, but also by CMS to ensure LTSS is truly person-centered.

Limitations and Future Research

When interpreting our findings, readers should note a number of limitations, particularly related to our sample. The majority of our participants were White, which is not representative of the IDD community. While our sample represented 21 states, it was also not representative of the United States as a whole as three states (New York, South Dakota, and Tennessee) had the most representation. There was also an unequal distribution across the residence types, with fewer participants in ICFDD, host family/family foster care, state-operated HCBS group homes, and other settings. Readers should also note that as this was a secondary data analysis, we could not add additional questions or additional research variables. Finally, as this study was not experimental design, we cannot draw causal conclusions.

We believe readers should interpret these limitations as invitations for future research. In addition to replicating with a stronger design, future research should determine if our findings are replicable with more evenly distributed samples as well as explore residence type further by examining the impact of residence size and provider size to determine if, and how, they impact personal outcomes. In addition to residence type, it may also be beneficial to compare different funding mechanisms (e.g., Medicaid ICFDD, Medicaid HCBS, Medicare, private pay, etc.) directly. We also believe it would be fruitful for future research to explore each factor in more depth by examining differences in personal outcomes by residence types on each of the individual indicators that make up each factor (i.e., Table 3). For example, although the factor Human Security did not significantly differ across many of the residence types, perhaps there would be differences between safety, rights, or respect in different settings. This research would also be particularly useful to explore the impact of transinstitutionalization on each of the 21 different indicators.

Conclusion

There have been significant changes in the disability LTSS system in the United States, including a significant decrease in state institution censuses, because of civil rights laws such as the Americans with Disabilities Act (ADA), litigation such as *Olmstead*, and advocacy by people with IDD and their families. For these reasons, this study aimed to explore if and how residence type impacts attainment of personal outcomes by people with IDD. Our findings suggest that although individual and family homes continue to result in the best possible quality of life outcomes of people with IDD compared to other settings, much of what has historically been considered deinstitutionalization of people with IDD may really be transinstitutionalization when it comes to provider owned or operated settings. Many provider ““services today have become

standardized, inflexible and unaccountable to those they serve” (Spagnuolo, 2016, n.p.). While much of this standardization and inflexibility is due to a lack of workforce stability, and limited financial resources, a systemic overhaul of LTSS is needed to detach from traditional custodial congregate care models by removing institutional biases, expanding funding for community based LTSS to build up a proper community infrastructure, supporting family members, and changing the culture of providers; all of which will result in an increased quality of life of people with IDD.

References

- American Network of Community Options and Resources. (2014). *Ensuring a sustainable work force for people with disabilities: Minimum wage increases can not leave direct support professionals behind*. Alexandria, VA: Author.
- Beadle-Brown, J., Leigh, J., Whelton, B., Richardson, L., Beecham, J., Baumker, T., & Bradshaw, J. (2016). Quality of life and quality of support for people with severe intellectual disability and complex needs. *Journal of Applied Research in Intellectual Disabilities*, 29(5), 409-421. <https://doi.org/10.1111/jar.12200>.
- Blair, T. R., & Espinoza, R. T. (2015). Medicare, Medicaid, and mental health care: historical perspectives on reforms before the US congress. *Jama*, 314(21), 2231-2232. <https://doi.org/10.1001/jama.2015.13328>.
- Braddock, D. (2007). Washington rises. Public financial support for intellectual disability in the United States, 1955–2004. *Mental Retardation and Developmental Disabilities Research Reviews*, 13(2), 169-177. <https://doi.org/10.1002/mrdd.20150>.
- Braddock, D., Hemp, R., Rizzolo, M. C., Tanis, E. S., Haffer, L., & Wu, J. (2015). *The state of the states in intellectual and developmental disabilities: Emerging from the great recession* (10th ed.). Washington, DC: The American Association on Intellectual and Developmental Disabilities.
- Braddock, D., Hemp, R., Tanis, E. S., Wu, J., & Haffer, L. (2017). *The state of the states in intellectual and developmental disabilities: 2017* (11th ed.). Washington, DC: The American Association on Intellectual and Developmental Disabilities.
- Carlson, L. (2010). *The faces of intellectual disability: Philosophical reflections*. Bloomington: Indiana UP.

Centers for Medicare and Medicaid Services. (2014a). Fact sheet: Summary of key provisions of the 1915(c) Home and Community-Based Services (HCBS) waivers final rule (CMS 2249-F/2296-F). Retrieved from <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/1915c-fact-sheet.pdf>

Centers for Medicare and Medicaid Services. (2014b). *Medicaid Program; State Plan Home and Community-Based Services, 5-year period for waivers, provider payment reassignment, and Home and Community-Based Setting requirements for Community First Choice and Home and Community-Based Services (HCBS) waivers (CMS 2249-F/2296-F)*. (CMS-2249-F). Washington, DC: Department of Health & Human Services.

Centers for Medicare and Medicaid Services. (2016). *Place of service codes for professional claims: Database (updated November 2016)*. Retrieved from https://www.cms.gov/Medicare/Coding/place-of-service-codes/Place_of_Service_Code_Set.html

Centers for Medicare and Medicaid Services. (n.d.-a). Glossary. Retrieved from <https://www.cms.gov/apps/glossary/>

Centers for Medicare and Medicaid Services. (n.d.-b). *ICF/IID glossary*. Retrieved from https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandCompliance/Downloads/ICFMR_Glossary.pdf

Clifford, S. A. (2006). *The politics of autism: expanding the location of care*. Ohio University,

Cooperrider, D. L., Peter Jr, F. S., Whitney, D., & Yaeger, T. F. (2000). Appreciative inquiry: Rethinking human organization toward a positive theory of change. *Team Performance Management*, 6(7-8), 140-140

- Cooperrider, D. L., & Srivastva, S. (1987). Appreciative inquiry in organizational life. *Research in organizational change and development*, 1(1), 129-169
- Crossley, M. (2017). Community integration of people with disabilities: Can Olmstead protect against retrenchment? *Laws*, 6(4), 22. <https://doi.org/10.3390/laws6040022>.
- Cullen, C., Whoriskey, M., Mackenzie, K., Mitchell, W., Ralston, K., Shreeve, S., & Stanley, A. (1995). The effects of deinstitutionalization on adults with learning disabilities. *Journal of Intellectual Disability Research*, 39(6), 484-494. <https://doi.org/10.1111/j.1365-2788.1995.tb00568.x>.
- Felce, D. (1997). Defining and applying the concept of quality of life. *Journal of Intellectual Disability Research*, 41(2), 126-135
- Forrester-Jones, R., Carpenter, J., Cambridge, P., Tate, A., Hallam, A., Knapp, M., & Beecham, J. (2002). The quality of life of people 12 years after resettlement from long stay hospitals: Users' views on their living environment, daily activities and future aspirations. *Disability & Society*, 17(7), 741-758. <https://doi.org/10.1080/0968759021000068469>.
- Frank, R. G., Goldman, H. H., & Hogan, M. (2003). Medicaid and mental health: be careful what you ask for. *Health Affairs*, 22(1), 101-113. <https://doi.org/10.1377/hlthaff.22.1.101>.
- Friedman, C. (2017a). Expanding stakeholder knowledge of the Home and Community Based Services (HCBS) settings rule. *Inclusion*, 5(3), 203-212. <https://doi.org/10.1352/2326-6988-5.3.203>.
- Friedman, C. (2017b). A national analysis of Medicaid Home and Community Based Services waivers for people with intellectual and developmental disabilities: FY 2015. *Intellectual and Developmental Disabilities*, 55(5), 281-302. <https://doi.org/10.1352/1934-9556-55.5.281>.

Friedman, C. (2017c). The Personal Outcome Measures[®]. *Disability and health journal, Online ahead of print*. <https://doi.org/10.1016/j.dhjo.2017.12.003>.

Friedman, C., Lulinski, A., & Rizzolo, M. C. (2015). Mental/behavioral health services: Medicaid Home and Community-Based Services 1915(c) waiver allocation for people with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities, 53*(4), 257-270. <https://doi.org/10.1352/1934-9556-53.4.257>.

Friedman, C., & Rizzolo, M. C. (2016). Un/Paid labor: Medicaid Home and Community Based Services waivers that pay family as personal care providers. *Intellectual and Developmental Disabilities, 54*(4), 233-244. <https://doi.org/10.1352/1934-9556-54.4.233>.

Gallanis, T. P., & Gittler, J. (2012). Family caregiving and the law of succession: A proposal. *University of Michigan Journal of Law Reform, 45*(4), 13-12

Gidley, J. M., Hampson, G. P., Wheeler, L., & Bereded-Samuel, E. (2010). From access to success: An integrated approach to quality higher education informed by social inclusion theory and practice. *Higher Education Policy, 23*(1), 123-147. <https://doi.org/10.1057/hep.2009.24>.

Hall, I., Strydom, A., Richards, M., Hardy, R., Bernal, J., & Wadsworth, M. (2005). Social outcomes in adulthood of children with intellectual impairment: Evidence from a birth cohort. *Journal of Intellectual Disability Research, 49*(3), 171-182

Hemp, R., Braddock, D., & King, M. (2014). Community-based Medicaid funding for people with intellectual and developmental disabilities. *National Conference of State Legislatures LegisBrief, 22*, 1-2

- Hewitt, A. (2014). Presidential address, 2014—Embracing complexity: Community inclusion, participation, and citizenship. *Intellectual and Developmental Disabilities*, 52(6), 475-495. <https://doi.org/10.1352/1934-9556-52.6.475>.
- Indiana Family & Social Services Administration. (2016). Home and Community-Based Services (HCBS) Final Rule and Indiana's HCBS statewide transition plan (STP). Retrieved from https://www.in.gov/fssa/files/HCBS_Information_for_AMHH_and_BPHC_Providers_2-17-16.pdf
- Larson, S., Lakin, C., & Hill, S. (2013). Behavioral outcomes of moving from institutional to community living for people with intellectual and developmental disabilities: U.S. studies from 1977 to 2010. *Research and Practice for Persons with Severe Disabilities*, 37(4), 235-246. <https://doi.org/10.2511/027494813805327287>.
- Larson, S. A., Hallas-Muchow, L., Aiken, F., Taylor, B., Pettingell, S., Hewitt, A., . . . Fay, M. L. (2016). *In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2013*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Ligas Consent Decree Monitor. (2016). *Stanley Ligas, et al. v. Felicia Norwood, et al.: Fourth annual report of the Monitor*.
- Ligas Consent Decree Monitor. (2017). *Stanley Ligas, et al. v. Felicia Norwood, et al.: Fifth annual report of the Monitor*.

- Lulinski-Norris, A. (2014). *Community capacity to provide mental and behavioral health services to people with developmental disabilities*. Paper presented at the Department of Disability and Human Development, University of Illinois at Chicago, Chicago.
- Mansell, J., & Beadle-Brown, J. (2004). Person-centred planning or person-centred action? Policy and practice in intellectual disability services. *Journal of Applied Research in Intellectual Disabilities, 17*, 1-9. <https://doi.org/10.1111/j.1468-3148.2004.00175.x>.
- O'Mahony, C. (2013). *Diversion: A comparative study of law and policy relating to defendants and offenders with mental health problems and intellectual disability*.
- Olmstead v. LC, No. 98-536, 527 581 (Supreme Court 1999).
- Oregon Department of Human Services. (n.d.). Adults with intellectual or developmental disabilities foster home program overview.
- Prins, S. J. (2011). Does transinstitutionalization explain the overrepresentation of people with serious mental illnesses in the criminal justice system? *Community mental health journal, 47*(6), 716-722. <https://doi.org/10.1007/s10597-011-9420-y>.
- Rizzolo, M. C., Hemp, R., Braddock, D., & Schindler, A. (2009). Family support services for persons with intellectual and developmental disabilities: Recent national trends. *Intellectual and Developmental Disabilities, 47*(2), 152-155. <https://doi.org/10.1352/1934-9556-47.2.152>.
- Sisti, D. A., Segal, A. G., & Emanuel, E. J. (2015). Improving long-term psychiatric care: bring back the asylum. *Jama, 313*(3), 243-244. <https://doi.org/10.1001/jama.2014.16088>.
- Spagnuolo, N. (2016). Building back wards in a 'post' institutional era: Hospital confinement, group home eviction, and Ontario's treatment of people labelled with intellectual disabilities. *Disability Studies Quarterly, 36*(4). <https://doi.org/10.18061/dsq.v36i4.5279>.

The Council on Quality and Leadership. (2017a). *The Personal Outcome Measures® 2017:*

Measuring outcomes now and into the future. Towson, MD: The Council on Quality and Leadership.

The Council on Quality and Leadership. (2017b). *Personal Outcome Measures®: Measuring personal quality of life* (3rd ed.). Towson, MD: Author.

Trent, J. W. J. (1994). *Inventing the feeble mind: A history of mental retardation in the United States.* Berkley: University of California Press.

Wachtler, S., & Bagala, K. (2013). From the asylum to solitary: transinstitutionalization. *Alb. L. Rev.*, 77, 915

Table 1

Demographics of Sample (n = 1,341)

Characteristic	<i>n</i>	%	Characteristic (cont.)	<i>n</i>	%
Age range			Primary method of communication		
18 to 24	95	7.1	Verbal/spoken language	1102	82.2
25 to 34	250	18.6	Face/body expression	169	12.6
35 to 44	223	16.6	Sign language	16	1.2
45 to 54	279	20.8	Communication device	14	1.0
55 to 64	252	18.8	Other	33	2.5
65 to 74	122	9.1	Impairment level		
75+	39	2.9	Less severe impairments	971	72
Gender			Severe impairments	370	28
Man	719	53.6	Residence type		
Woman	613	45.7	Own home	284	21
Race			Family home	213	16
White	998	74.4	Provider owned/operated home	677	51
Black or African American	246	18.3	State-operated HCBS group home	43	3.2
American Indian or Alaska Native	54	4.0	ICFDD (private and state)	47	3.5
Hispanic, Latinx, or Spanish Origin	29	2.2	other	51	3.8
Other (Asian, Native Hawaiian, other Pacific Islander, or other)	16	1.2			

Note. ICFDD = Intermediate care facility for people with developmental disabilities. HCBS = Home and community based services. DSP = direct support professionals.

Table 2

Residence Type Descriptions

Residence Type	Description
Own homes	When a person lives in their own home or apartment.
Family homes	People living with their family in their natural home.
Provider owned or operated home	Residential setting and a specific "physical place that is owned, co-owned, and/or operated by a provider...[where an] individual resides" (Indiana Family & Social Services Administration, 2016, p. 7). These settings are often also licensed by the state. Group homes are an example of provider owned or operated homes.
Intermediate care facilities for individuals with developmental disabilities (ICFDD)	An institutional "facility which primarily provides health-related care and services above the level of custodial care to [IDD] individuals but does not provide the level of care available in a hospital or skilled nursing facility" (Centers for Medicare and Medicaid Services, n.d.-a., n.p.). "Institutions' (4 or more beds) for individuals with intellectual disabilities... must provide 'active treatment'...in a protected residential setting, ongoing evaluation, planning, 24-hour supervision, coordination, and integration of health or rehabilitative services" (Centers for Medicare and Medicaid Services, n.d.-b, p. 1-2) ICFDD can be public (state run) or private.
State-operated HCBS group home	A community based "residence, with shared living areas, where clients receive supervision and other services such as social and/or behavioral services, custodial service, and minimal services (e.g., medication administration)" (Centers for Medicare and Medicaid Services, 2016, n.p.). Although group homes size regulations can vary by state, most are smaller than ICFDD. These particular group homes are run by the state; this is most common in New York state.
Other settings	
Host family/family foster care	Community residential settings, typically an individual home, that mirror child foster care but are designed for adults with IDD that do not need skilled nursing. These "single-family residences offer 24-hour care in a home-like setting that is safe and secure...Adult foster home providers provide meals, transportation to appointments and other activities, medication management, assistance with activities of daily living, personal care, mobility, and household activities...The goal is to provide necessary care while emphasizing the individual's independence" (Oregon Department of Human Services, n.d., n.p.)
Assisted living facility	Comprehensive care "in which personal care services such as meals, housekeeping, transportation, and assistance with activities of daily living are available as needed to people who still live on their own in a residential facility. In most cases, the 'assisted living' residents pay a regular monthly rent. Then, they typically pay additional fees for the services they get" (Centers for Medicare and Medicaid Services, n.d.-a, n.p.).
Nursing home	A 24-hour comprehensive care setting "that provides a room, meals, and help with activities of daily living and recreation. Generally, nursing home residents have physical or mental problems that keep them from living on their own. They usually require daily assistance." (Centers for Medicare and Medicaid Services, n.d.-a, n.p.) Nursing homes are a form of institution.
Transitional housing	Short-term temporary housing focused on practicing independent living to help people transition between settings (e.g., between institutions and community, from homelessness or prison, etc.).

Note. HCBS = Home and Community Based Services.

Table 3

The Personal Outcome Measures[®]

Factors and indicators

FACTOR 1: MY HUMAN SECURITY

People are safe
People are free from abuse and neglect
People have the best possible health
People experience continuity and security
People exercise rights
People are treated fairly
People are respected

FACTOR 2: MY COMMUNITY

People use their environments
Live in integrated environments
Interact with other members of the community
Participate in the life of the community

FACTOR 3: MY RELATIONSHIPS

People are connected to natural supports
People have friends
People have intimate relationships
People decide when to share personal information
People perform different social roles

FACTOR 4: MY CHOICES

People choose where and with whom to live
People choose where to work
People choose services

FACTOR 5: MY GOALS

People choose personal goals
People realize personal goals

Table 4

Descriptive Statistics

	<i>M (SD)</i>				
	My Human Security (<i>n</i> = 7)	My Community (<i>n</i> = 4)	My Relationships (<i>n</i> = 5)	My Choices (<i>n</i> = 3)	My Goals (<i>n</i> = 2)
<i>Overall M</i>	3.82 (1.74)	2.22 (1.39)	2.28 (1.59)	0.87 (1.03)	1.01 (0.80)
Residence Type					
Own home	3.82 (1.69)	2.74 (1.21)	2.32 (1.64)	1.28 (1.19)	1.13 (0.83)
Family home	4.34 (1.58)	2.89 (1.21)	2.88 (1.49)	0.95 (1.10)	0.96 (0.78)
Provider owned/operated home	3.70 (1.76)	1.90 (1.37)	2.05 (1.53)	0.71 (0.90)	0.95 (0.78)
State-operated HCBS group home	3.92 (1.73)	1.50 (1.39)	2.68 (1.65)	0.84 (1.15)	1.00 (0.77)
ICFDD	3.29 (1.78)	1.44 (1.27)	2.20 (1.69)	0.60 (0.89)	1.27 (0.72)
other	3.94 (1.86)	2.50 (1.29)	2.23 (1.72)	.94 (1.12)	1.21 (0.87)
Impairment severity					
Less severe impairments	3.95 (1.71)	2.39 (1.37)	2.34 (1.57)	0.93 (1.06)	1.00 (0.80)
Severe impairments	3.52 (1.77)	1.88 (1.36)	2.10 (1.62)	0.77 (1.00)	1.05 (0.78)

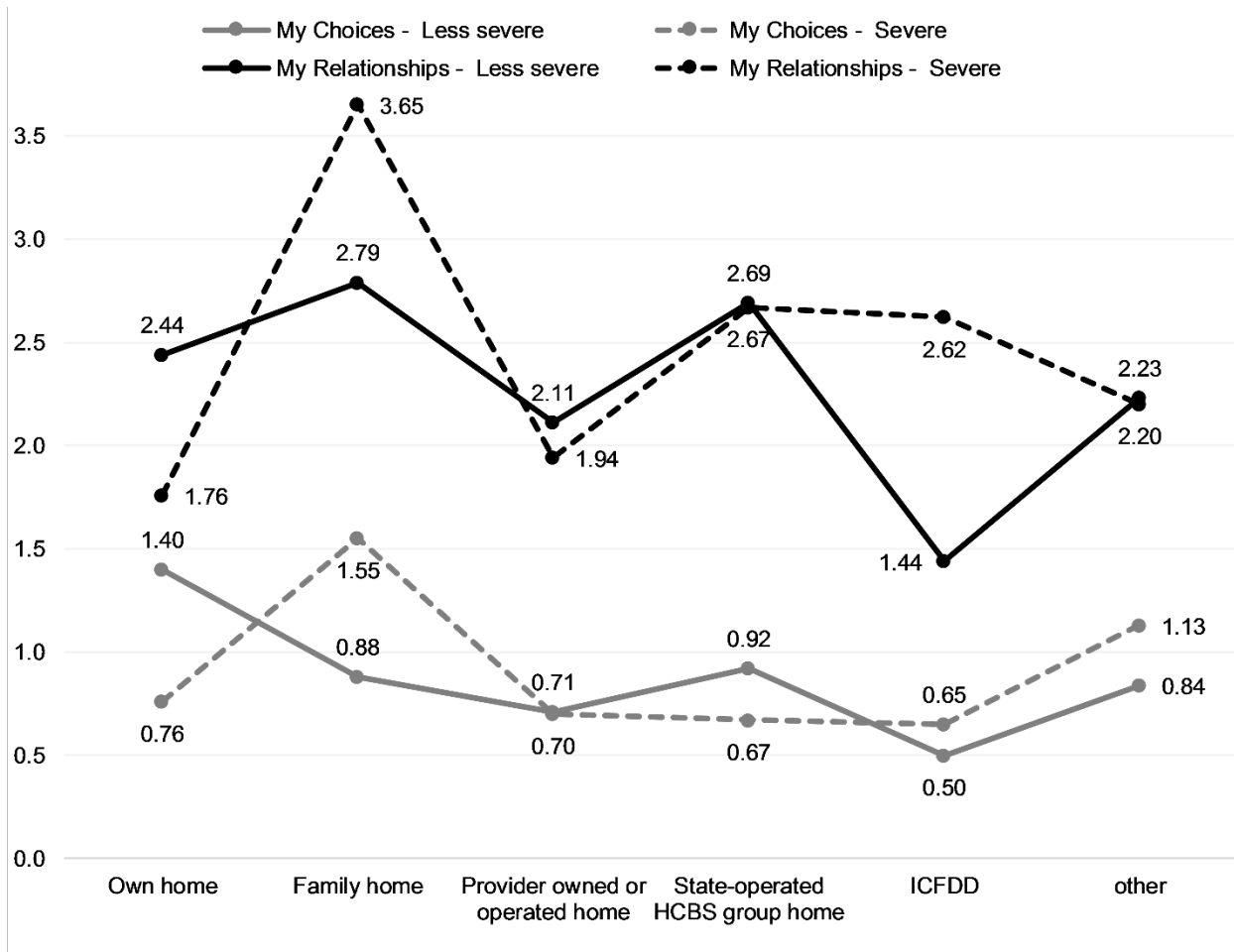


Figure 1. Interaction effects between residence type, and severe and less severe impairments for relationships and choices factors.

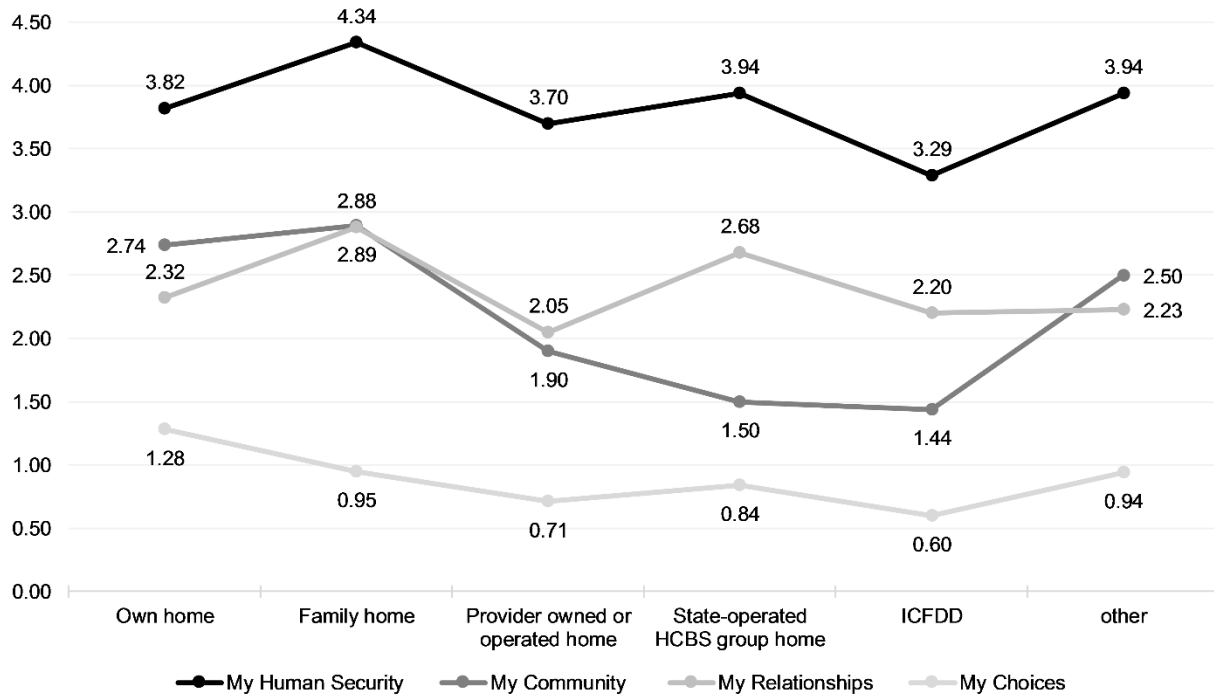


Figure 2. Main effects of residence type on the four significant factors: human security, community, relationships, and choices.