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Residential Transitions among Adults with Intellectual Disability across 20 Years

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Abstract

The present study addresses critical gaps in the literature by examining residential transitions among 303 adults with intellectual disability over 10 years (Part 1) and 75 adults with Down syndrome over 20 years (Part 2). All adults lived at home at the start of the study, but many moved to a variety of settings. Several characteristics of the adults with intellectual disability differed across settings, most notably adaptive behavior and the number of residential transitions, while characteristics such as age, type of disability, and behavior problems were less predictive of residential placements. The number of moves over the course of the study varied widely, with critical links to earlier family dynamics, social relationships, and health and adaptive behavior.

Recent reports estimate 1.3 million adults in the United States have an intellectual disability (Brault, 2010). Intellectual disability is characterized by limitations in intellectual functioning and behavioral adaptations to environmental demands that begin early in life (Schalock, Luckasson, & Shogren, 2007). Down syndrome is the most common known genetic cause of intellectual disability, diagnosed in approximately 14 out of 10,000 live births (Parker et al., 2010). As a result of improvements in medicine, technology, and education, the life expectancy of individuals with intellectual disability is nearly comparable to the general population in the United States (Bittles et al., 2002). As more individuals with intellectual disability age into adulthood, they are increasingly likely to move away from the parental home and require residential services for greater lengths of time.

The demand for residential services is therefore on the rise. The number of people with intellectual disability receiving residential services grew from 267,682 in 1988 (Lakin, Prouty, Polister, & Coucouvanis, 2003) to 460,597 in 2011 (Larson, Salmi, Smith, Anderson, & Hewitt, 2013). Stemming from landmark legislation in the 1960s (CMHA; P.L. 88-164) and 1980s (OBRA; P.L. 100-203), the number of individuals with intellectual disability living in state institutions and nursing homes has steadily declined. Concurrently, there has been rapid growth in the number of small residential settings. The percentage of

individuals with intellectual disability living in settings with fewer than 6 residents rose from 29% in 1988 (Salmi, Scott, Webster, Larson, & Lakin, 2010) to 75% in 2011 (Larson et al., 2013). This growth in small residences can be attributed in part to the rising number of individuals with intellectual disability living in their own home or in foster family settings. The number of people with intellectual disability living in their own home, either rented or owned by themselves, doubled from 1998 to 2011 (Larson et al., 2013).

The shift towards smaller, more diverse residential settings is apparent in a national study of the residential settings of individuals with intellectual disability (Tichá et al., 2012). Participants reported a variety of living arrangements, including group homes, agency owned or operated apartments, specialized institutions for persons with intellectual disability, nursing homes, homes of parents or relatives, host or foster homes, and homes owned or leased by the individual with intellectual disability. Adults with Down syndrome, like other individuals with intellectual disability, live in diverse residential settings. Compared to adults with other intellectual disabilities, Stancliffe and colleagues (2012) found adults with Down syndrome to be more likely to live in the family home and less likely to live in an institution or their own home.

Much of the extant literature has focused on comparing quality of life outcomes in congregate versus community settings, with most studies demonstrating the relative advantage of community settings (Kozma, Mansell, & Beadle-Brown, 2009). These comparisons do not advance our understanding of outcomes across the diverse community settings available to adults with intellectual disability today, however. Moreover, the majority of studies have focused on the first move during adulthood. Placements outside of the home are likely to be prompted by declining health among mothers (Essex, Seltzer, & Krauss, 1997) or adults with intellectual disability (Jokinen, Janicki, Hogan, & Force, 2012) and aging among adults with intellectual disability (Essex et al., 1997). Family dysfunction unrelated to the child with intellectual disability may also prompt relocation from the family home (Alborz, 2003).

Considerably less is known about subsequent moves experienced by individuals with intellectual disability. Krauss and Erickson (1988) reported that adults with intellectual disability living in community residences retrospectively reported an average of 4.1 previous residential placements in their lifetime. Adults with Down syndrome may be at higher risk of experiencing relocations than adults with other intellectual disabilities. Patti, Amble, and Flory (2005) reported 60% of adults with Down syndrome to experience one or more residential relocations within a five-year period as compared to only 21% of adults with other intellectual disabilities of the same age. Exposure to recurrent relocations may lead to emotional, affective, and behavior problems for individuals with intellectual disability (Hamilton, Sutherland, & Iacono, 2005). Adults with Down syndrome have been shown to be particularly sensitive to transitions (Hamilton et al., 2005) and changes in routine (Haveman, Maaskant, Van Schrojenstein Lantman-de Valk, Urlings, & Kessels, 1994).

Little research has examined antecedents of residential transitions prospectively. Family relationships have an important influence on the social and psychological well-being of individuals with intellectual disability living outside the home (Seltzer, Krauss, Hong, &

Orsmond, 2001). Family involvement has been identified as an important predictor of adjustment to relocation (Schalock & Lilley, 1986) and community integration (Heller, Miller, & Hsieh, 2002) among individuals with intellectual disability living outside of the home. Beyond the family emotional climate, other social relationships may influence the stability of residential placements. Existing literature supports the importance of social support networks to individuals with intellectual disability in their adaptation to residential transitions (Jacobson & Kropf, 1993; Jokinen et al., 2012).

Individuals with intellectual disability are experiencing more complex residential transitions and living arrangements than previously, warranting further investigation into the impact of residential transitions and placements on well-being. The present study addresses critical gaps in the literature by examining residential transitions among adults with intellectual disability over a ten year period (Part 1) using data from a prospective, longitudinal study. In a separate set of analyses (Part 2), residential transitions among a subsample of adults with Down syndrome were examined over a twenty year period. The addition of Part 2 permitted exploration of antecedents and outcomes of transitions over a greater length of time.

In contrast with previous work in this area, the current analyses consider heterogeneity in the number of transitions and residential arrangements as well as the antecedents of residential transitions. There are parallel research aims for Part 1 and Part 2. The first aim is to describe and compare the residential settings of adults with intellectual disability. Settings will be compared on characteristics of the adult with intellectual disability (adaptive behavior, health, behavior problems) and the number of moves experienced over the course of the study. The second aim is to examine which characteristics of the adults with intellectual disability (age, gender, adaptive behavior, health, social support) and their families (income, size, conflict, maternal health), measured while co-residing at the start of the study, predict the number of residential transitions experienced over the course of the study.

Method

Participants

Data were drawn from a larger longitudinal study of 461 families raising children with intellectual disability. The first eight waves of data collection (T1-T8) were collected at 18 month intervals from 1988 to 2000. The final wave of data collection (T9) took place 10 years later (2010/2011) and included only adults with Down syndrome. At the outset of the study, the son or daughter with intellectual disability was living at home with a mother between the ages of 55 and 85 (Krauss & Seltzer, 1999). Half of the respondents lived in Massachusetts and half lived in Wisconsin. Data collection procedures were identical in both states. The mother served as the primary respondent at each wave unless she either died or became incapacitated, in which case a “successor caregiver” served as the primary respondent. If the mother was not alive or well enough to participate, fathers served as the primary respondent. If neither the mother nor the father were alive or well enough to participate, an adult sibling served as the respondent. Other relative or non-relative caregivers were identified in the event that siblings were unable to participate.

Part 1: Adults with intellectual disability (n=362)—Part 1 of the present study includes data from 362 adults with intellectual disability from the first eight waves of data collection (T1-T8). Three hundred and sixty four families participated in the study at T8. From the original sample, 35 were deceased and 62 were unable to be located or declined to participate. Two cases were excluded due to incomplete residential history data. Of the 362 adults in the sample for Part 1, 133 had Down syndrome and 71 of these were included in the sample for Part 2. Adults with intellectual disability ranged in age from 25 to 68 ($M = 43.94$, $SD = 7.30$) at T8 and 55% were male.

The mother remained the primary respondent in 303 families. Two-thirds (66%) of mothers co-resided with their child with intellectual disability at the time of the T8 interview. Mothers ranged in age from 64 to 95 years of age ($M = 75.04$, $SD = 5.99$) at T8. Fathers served as primary respondents in 14 families and ranged in age from 65 to 91 years of age ($M = 77.38$, $SD = 7.38$). Among fathers, 64% co-resided with their child with intellectual disability at T8. For 39 families, an adult sibling served as the respondent. Siblings ranged in age from 38 to 63 years of age ($M = 51.02$, $SD = 6.04$). The majority (62%) of sibling respondents were sisters. Less than one quarter (21%) of sibling respondents were co-residing with their sibling with intellectual disability at the time of the T8 interview. In one family, the adult's cousin served as primary respondent (age 44 years). In the remaining 5 families, the primary respondent was a non-relative. None of the non-relative or other relative respondents were co-residing with the adult with intellectual disability. Descriptive statistics on demographic characteristics at T1 are presented in Table 2.

The sample for Part 1 of the study was compared to the 64 families in the original sample that did not participate at T8, excluding the 35 families in which the adult was deceased at the time of the T8 interview. At the start of the study (T1), families included in the sample for Part 1 reported higher family income, $t(401) = -3.71$, $p < .01$, and higher maternal education, $t(420) = -4.11$, $p < .01$, than other families. There were no significant differences in maternal age, $t(420) = 1.80$, $p = .07$ or marital status, $\chi^2(4, N = 422) = 4.46$, $p = .35$, at T1. Families who participated in the study at T8 were more likely to be from Wisconsin than other families, $\chi^2(1, N = 422) = 21.56$, $p < .01$. With respect to the adult with intellectual disability, there were no significant differences in level of intellectual disability, $\chi^2(3, N = 411) = 5.41$, $p = .14$, gender, $\chi^2(1, N = 422) = .09$, $p = .76$, adaptive behavior, $t(420) = -.95$, $p = .34$, or health, $t(420) = -.24$, $p = .81$, between adults who participated in the study at T8 and those who dropped out. Adults with intellectual disability who continued to participate were significantly younger than the other adults at the start of the study, $t(420) = .356$, $p < .01$.

Part 2: Adults with Down syndrome (n=75)—Part 2 of the present study includes data from 75 adults with Down syndrome across nine waves of data collection (T1-T9). From the original sample of 169 adults with Down syndrome, 58 were deceased and 32 were unable to be located or declined to participate at T9. An additional 4 adults with Down syndrome had no surviving family members to contact. Four of the adults with Down syndrome who participated at T9 were excluded from the sample in Part 1 due to missing data at T8. Adults with Down syndrome ranged in age from 37 to 65 ($M = 51.1$, $SD = 6.6$) at T9 and 65% were male.

Mothers remained the primary respondent in 34 families at T9. These mothers ranged in age from 76 to 97 years of age ($M = 84.5$, $SD = 5.1$). Over one third (38%) of mothers co-resided with their child with Down syndrome. Fathers served as primary respondents in 6 families, with only one father co-resided with his child with Down syndrome. Fathers ranged in age from 80 to 85 years of age ($M = 82.3$, $SD = 1.9$). Siblings served as primary respondents in the remaining 35 families, of which 35% were co-residing with their sibling with Down syndrome. Siblings ranged in age from 39 to 74 ($M = 60.0$, $SD = 7.2$). The majority of siblings were sisters (71.4%). Descriptive statistics on demographic characteristics at T1 are presented in Table 2.

The sample for Part 2 of the study was compared to the 37 other families in the original sample with adults with Down syndrome that did not participate at T9, excluding the 57 families in which the adult with Down syndrome was deceased at the time of the T9 interview. At the start of the study (T1), families in the sample for Part 2 reported higher maternal education, $t(110) = -2.01$, $p = .05$, than other families. There were no significant differences in family income, $t(108) = -1.92$, $p = .06$, maternal age, $t(110) = 1.47$, $p = .15$, or marital status, $\chi^2(2, N = 112) = 4.20$, $p = .12$, at T1. Families who participated in the study at T9 were not more likely to be from Wisconsin than other families, $\chi^2(1, N = 112) = 2.46$, $p = .12$. With respect to the adult with Down syndrome, there were no significant differences in level of intellectual disability, $\chi^2(3, N = 112) = .77$, $p = .86$, gender, $\chi^2(1, N = 112) = 1.33$, $p = .25$, age, $t(110) = 1.47$, $p = .14$, or adaptive behavior, $t(110) = -1.50$, $p = .14$, between adults who participated in the study at T9 and those who dropped out. Adults with Down syndrome who continued to participate reported significantly better health than other adults with Down syndrome at the start of the study, $t(110) = -2.45$, $p = .02$.

Measures

Family demographics—The present analyses use information on family income collected during interviews at T1. Standardized scores (z-scores) were created to represent each family's income relative to the other families in the sample. Family size was based on the number of adults and children in the immediate family at T1.

Family conflict—Mothers completed the Family Environment Scale-Second Edition (FES; Moos & Moos, 1986) at T1. Mothers were asked to indicate whether 9 statements about families were true/mostly true or false/mostly false for most members of their family. The Conflict subscale measures the amount of openly expressed anger, aggression, and conflict among family members. The FES has demonstrated good internal consistency and stability (Moos & Moos, 2002) and strong convergent validity with other self-report and observational measures (Sanford, Bingham, & Zucker, 1999). Internal consistency for the Conflict subscale was $\alpha = .61$ in the present sample.

Health—Health status was assessed using a global rating of current health on a 4-point Likert scale (1 = *very poor/poor*, 2 = *fair*, 3 = *good*, 4 = *excellent*) at T1, T8 and T9. Mothers reported on their own health at T1. Such global self-ratings of health have been found to be accurate measures of health status (Benyamini, 2011). Mothers also reported on the health of their son or daughter with intellectual disability at T1. There is emerging evidence that

proxy report of health status is equally valid to self-report (Satoe et al., 2012; Theunissen et al., 1998). In the project from which data for the present study were drawn ($N=461$), mothers' global ratings of their son or daughter's health at the start of the study (1988) predicted current mortality (2013), $b = -.57$, $Wald(1) = 17.61$, $p < .01$. At T8 and T9, the health of the adult with intellectual disability was rated by the primary respondent.

Adaptive behavior—Adaptive behavior of the son or daughter with Down syndrome was assessed using the Waisman Activities of Daily Living Scale (W-ADL; Maenner et al., 2012) at T1, T8 and T9. The primary respondent was asked to rate the independence of the adult with intellectual disability in 17 activities of daily living (e.g., prepare simple foods, grooming) on a 3-point scale (0 = *does not do at all*, 1 = *could do but does not/does with help*, 2 = *independent*). The W-ADL has demonstrated strong internal consistency and criterion and construct validity for adolescents and adults with intellectual disability (Maenner et al., 2012). Internal consistency in the present sample was $\alpha = .94$ at T1, T8 and T9.

Social support—The social support networks of the adult with intellectual disability were assessed during interviews with mothers at T1 based on items drawn from the Antonucci (1986) convoy model. Mothers identified the people in her child's life with whom there was a special bond. Detailed information was collected on up to 10 individuals, including age, number of years known, geographic proximity (0 = *not within hour's drive*, 1 = *within hour's drive*), frequency of contact (from 0 = *never* to 7 = *daily*), and whether or not this individual was also part of the mother's social network (0 = *not in mother's network*, 1 = *in mother's network*). These factors were averaged across contacts in the adult's social network. Network size (number of individuals listed out of 10) was also calculated.

Behavior problems—Behavior problems were measured using the Scales of Independent Behavior-Revised (SIB-R; Bruininks, Woodcock, Weatherman, & Hill, 1996) at T2, T8 and T9. The primary respondent rated the frequency (1 = *less than once a month* to 5 = *1 or more times/hour*) and severity (1 = *not serious* to 5 = *extremely serious*) of the adult's behavior in the past 6 months. A summary score weighting frequency by severity across domains (internalizing, externalizing, asocial) was used for analyses. Reliability and validity have been established by Bruininks et al. (1996). Internal consistency for frequency and severity ratings was $\alpha = .81$ at T2 and T8 and $\alpha = .71$ at T9 for the present sample.

Dementia status—Dementia status of the adults with Down syndrome was classified using consensus coding between two licensed clinical psychologists blind to the study's hypotheses at T9, following the coding system reported in Silverman et al. (2004). Assessments utilized in the consensus coding included the following measures administered to the primary respondents at T9: Dementia Questionnaire for People with Learning Disabilities (Evenhuis, Kengen, & Eurlings, 2006), the Dementia Scale for Down Syndrome (Gedye, 1995), the Psychiatric Assessment Schedule for Adults with Developmental Disabilities (Moss, 2002), as well as reports of current and previous health conditions, current diagnoses, and current medication. In addition, we utilized respondent information collected in previous waves of data collection and prior longitudinal direct assessments of

cognitive ability from T2 and T3 to assist in coding cognitive declines based on previous cognitive abilities. Initial coding resulted in 89% agreement among the psychologists. Clinical discussion elucidated potential contributing causes to functional declines that resulted in 100% agreement among the psychologists on the final coding of dementia status. Fifty six adults with Down syndrome (74.7%) were identified as “no dementia”, 6 adults (8%) were identified as “possible dementia”, and 13 adults (17.3%) were identified as meeting criteria for “definite dementia”. Dementia status was categorized as (0) no dementia or (1) possible or definite dementia for the purposes of the present analyses.

Residential information—Residential information for the adult with intellectual disability was collected at each wave (T1-T9). If the adult moved since the previous interview, the primary respondent was asked to report the date the adult moved in and out of each prior residence as well as the type of residential setting. The number of moves was coded as 0 = *no moves*, 1 = *one move*, 2 = *two moves*, or 3 = *three or more moves*. Moves with the family were not counted for the purposes of the present analyses. The residential setting at T8 and T9 were coded according to the following categories: with relatives (with parents, with siblings), community living (group home/shared apartment with 100% supervision, foster home), semi-independent living (alone or with others with some but less than 100% supervision), independent living (alone or with others with no supervision), institution (public or private), and nursing home/hospital setting (nursing home, congregate care, hospital setting).

Analytic Plan

Distributions of continuous outcome variables were approximately normal, with the exception of behavior problems. Results did not differ for raw and transformed values, however, so the reported models use the raw values to facilitate interpretation. Missing data were imputed using the Markov Chain Monte Carlo procedure in SPSS version 19. For Part 1, since less than 2.91% of values were missing a single imputed data set was created, following recommendations in the literature (Widaman, 2006). Similarly, less than 1.49% of values were missing for Part 2 and a single imputed data set was created.

Parallel analyses were conducted for Part 1 and Part 2. To address the first research aim, descriptive statistics on residential information were first examined. Residential groups at T8 were examined in Part 1 and residential groups at T9 were examined in Part 2. Next, MANCOVAs were conducted to compare levels of adaptive behavior, health, and behavior problems as well as the number of residential transitions experienced over the course of the study for adults across residential settings, controlling for age. Analyses for Part 1 focused on the initial time point of data and T8 levels of adaptive behavior, health, and behavior problems while analyses for Part 2 focused on the initial time point of data and T9 levels of these measures as well as dementia status. Change over the course of the study was represented in absolute values (e.g., 5 scale points) as well as the percentage of the T1 standard deviation for that variable. For example, a 50% decline would indicate that the mean for that residential group declined approximately one half of a standard deviation from the start to the end of the study, controlling for age. For outcomes that violated the Levene's

test of equality in error variances, analyses were replicated using a post-hoc test which does not assume equal error variances (Dunnett's C).

To address the second research aim, a multinomial logistic regression was conducted with number of moves over the course of the study as the criterion variable. The number of moves was counted over a ten year period (T1-T8) in Part 1 and a twenty year period (T1-T9) in Part 2. The likelihood of moving once, twice, or three or more times was compared to the likelihood of never moving out of the family home in both analyses. Characteristics of the sons and daughters with intellectual disability (age, gender, adaptive behavior, health), aspects of their social network, and characteristics of their families measured at T1 were entered as predictors in both analyses.

Results

Preliminary analyses indicated no differences in outcomes by state (MA vs. WI) in Part 1 or Part 2 of the study. The findings for comparisons across residential settings at T8 and T9 did not differ when type of respondent (mother, father, sibling, other) was controlled, therefore type of respondent was omitted from the analyses. For outcomes that violated the Levene's test of equality in error variances, results did not differ using Dunnett's C post-hoc test.

Part 1: Analyses of Adults with Intellectual Disability ($n=362$)

Comparison of Residential Settings at T8—At T8, 66% of adults with intellectual disability were living with relatives. Community settings accounted for 24% of individuals, followed by semi- or fully-independent settings (6%), nursing home or hospital settings (4%). No individuals were living in public or private institutions. Semi- and fully-independent living categories were combined for the purposes of analysis since so few individuals were living in independent settings without supervision. The proportion of adults with Down syndrome did not differ across residential settings, $\chi^2(3, N=362) = 1.72, p = .63$. There were significant differences in age across residential groups, $F(3, 358) = 5.05, p < .01$. Adults living in nursing home/hospital settings ($M = 50.96, SD = 6.43$) were significantly older than adults living with relatives ($M = 43.69, SD = 7.09$), in the community ($M = 44.18, SD = 7.58$), or in semi- or fully-independent settings ($M = 41.59, SD = 6.88$).

As seen in Table 3, there were differences in the characteristics of adults with intellectual disability across residential settings, above and beyond age. Adults significantly differed in adaptive behavior at T8. Adults living in semi- or fully-independent living had significantly higher adaptive behavior than adults living in other settings. Adults living with relatives or in community settings had higher adaptive behavior than adults in nursing home/hospital settings. These group differences in adaptive behavior were also observed while the adults with intellectual disability were living in the family home at the start of the study (T1), with only one exception. At T1, the adaptive behavior of adults who later moved into nursing home/hospital settings did not significantly differ from adults who later moved into community settings. Rates of change in adaptive behavior were also compared across residential groups. Adults who lived in community settings at T8 experienced significantly greater growth in adaptive behavior over the course of the study than adults who lived with

relatives at T8. Adults living in community settings increased by over one quarter of a standard deviation while adults living with relatives increased by only 2% of a standard deviation.

There were significant overall group differences in health at T1 and T8. Adults living with relatives had higher physical health ratings than adults living in community settings at both time points at trend level only. There were trend level differences in the rate of change in health across groups. Decreases in health from T1 to T8 were sharper for adults in nursing home/hospital settings than for adults living with family or in the community, at trend level only. Adults living in nursing home/hospital settings declined over one standard deviation, while adults living with family or in the community declined less than one third of a standard deviation.

There were no significant group differences in behavior problems at T8. At T2 (when behavior problems were first measured), there were overall trend level differences across residential groups, although no individual group comparisons were significant. Rates of change in behavior problems did not differ across groups. In follow up analyses, there were no significant group differences in level or rate of change for the internalized, externalized, and asocial behavior subscales of the SIB-R.

Adults across residential settings differed in the number of moves they experienced over the course of the study. Adults who lived with relatives at T8 experienced significantly fewer transitions than adults in other settings.

T1 Predictors of Number of Residential Transitions—At T8, more than half of adults with intellectual disability (60%) remained in the parental home. Twenty one percent of adults moved only once during the study period, 10% moved twice, and 9% moved three or more times from 1988 to 2000. The number of moves ranged from 0 to 11 ($M = 0.77$, $SD = 1.29$). The number of total moves did not differ for adults with and without Down syndrome, $t(360) = -1.17$, $p = .24$. Among those who moved, age at the time of the first move ranged from 21 to 66 years ($M = 38.61$, $SD = 8.01$). Adults with Down syndrome were significantly younger when they first moved out of the parental home ($M = 35.95$, $SD = 7.30$) than adults without Down syndrome ($M = 40.20$, $SD = 8.09$), $t(127) = 3.01$, $p < .01$. Six adults returned to the family home after moving out.

Characteristics of the adult with intellectual disability and their family measured at the start of the study were examined as predictors of the number of transitions (Table 4). The only aspect of the adult's social network that was predictive of residential transitions, above and beyond other factors in a regression model, was the length of time the adult had known members of his or her social network at T1, therefore only this aspect of the social network was included in the final model for parsimony. Compared to never moving, the likelihood of moving once was increased by lower adaptive behavior and overall health. Higher family conflict and shorter relationships with members of their social network increased the likelihood that adults would move twice. Compared to never moving, the likelihood of moving three or more times was increased by lower maternal health, older age of the adult

and shorter relationships with members of their social network. Higher family conflict also increased the likelihood of moving three or more times, at trend level only.

Supplemental analyses revealed that, compared to the likelihood of moving once, the likelihood of moving twice or three or more times is increased by higher adaptive behavior (O.R. = 1.07, $p = .03$ and O.R. = 1.08, $p = .02$, respectively). The likelihood of moving three or more times was also increased at trend level by lower maternal health, O.R. = .59, $p = .10$, older age, O.R. = 1.08, $p = .052$, and better overall health, O.R. = 1.87, $p = .06$. Compared to the likelihood of moving twice, the likelihood of moving three or more times is increased by older age at trend level only, O.R. = 1.08, $p = .08$.

Part 2: Analyses of Adults with Down Syndrome ($n=75$)

Comparison of Residential Settings at T9—At T9, 35% of adults were living with relatives. Among those individuals, half were living with parents and half were living with adult siblings. Community settings accounted for 48% of individuals, followed by semi- or fully-independent settings (12%), and nursing home or hospital settings (5%). No individuals were living in public or private institutions. Semi- and fully-independent living categories were combined for the purposes of analysis since so few individuals were living in independent settings with no supervision. There were significant differences in age across residential groups, $F(3, 71) = 4.34$, $p < .01$. Adults living in nursing home/hospital settings ($M = 59.92$, $SD = 5.93$) were significantly older than adults living with relatives ($M = 49.27$, $SD = 6.23$), or in the community ($M = 50.75$, $SD = 4.91$), but not adults living in semi- or fully-independent settings ($M = 51.84$, $SD = 6.78$).

As seen in Table 5, there were differences in the characteristics of adults with Down syndrome across residential settings, above and beyond age. Adults significantly differed in their levels of adaptive behavior at T9. Adults living in semi- or fully-independent living had significantly higher adaptive behavior than adults living in other settings. Adults living with relatives had higher adaptive behavior than adults in nursing home/hospital settings. There were significant pre-existing group differences in adaptive behavior at T1. Adults who moved into semi- or fully-independent settings had higher adaptive behavior than adults who moved into community settings. Decreases in adaptive behavior from T1 to T9 were significantly sharper for adults in nursing home/hospital settings than adults in other settings. The mean level of adaptive behavior for adults living in nursing home/hospital settings declined over three standard deviations from T1 to T9.

There were significant group differences in overall health ratings at T9. Adults living with relatives had better physical health than adults living in nursing home/hospital settings, at trend level only ($p = .10$). There were no significant pre-existing group differences in health at T1. Decreases in health from T1 to T9 were sharper for adults in nursing home/hospital settings than for adults living with family at T9, at trend level only ($p = .10$). Adults in nursing home/hospital settings showed declines in health over 2.5 standard deviations. There were no significant group differences in behavior problems at T2 or T9. The rate of change in behavior problems did not differ across groups. In follow up analyses, there were no significant group differences in level or rate of change for the internalized, externalized, and asocial behavior subscales of the SIB-R.

Adults across residential settings differed in the number of moves they experienced over the course of the study. Adults who lived with relatives at T9 experienced significantly fewer transitions than adults living in community settings or semi- or fully-independent settings. The proportion of adults with possible or definite dementia differed across residential groups. Adults living in nursing home/hospital settings were more likely to have dementia than adults living with family members, controlling for age.

T1 Predictors of Number of Residential Transitions—From T1 to T9, 21% of the adults with Down syndrome did not move out of the parental home. In three cases, the parents either died or moved out of the home and a sibling or other caregiver moved in with the adult with Down syndrome. The remaining 13 adults continued to live with their parent(s). An additional 36% of participants moved once, 20% moved twice and the remaining 23% moved three or more times from 1988 to 2010/2011. The number of moves ranged from 0 to 7 ($M = 1.65$, $SD = 1.53$). Among those who moved, age at the time of the first move ranged from 21 to 62 years ($M = 40.73$, $SD = 9.48$). Only one adult returned to the parental home after moving out.

The only aspect of the adult's social network that was predictive of residential transitions, above and beyond other factors in a regression model, was the length of time the adult had known members of his or her social network at T1. Only this aspect of the social network was included in the final model for parsimony (Table 5). None of the T1 characteristics discriminated the likelihood of moving once from never moving. Higher family conflict, older age, and shorter relationships with members of the social network increased the likelihood that adults would move twice. Lower family income and higher family conflict increased the likelihood of moving three or more times. Supplemental analyses revealed that, compared to the likelihood of moving once, the likelihood of moving twice is increased by shorter relationships with members of the adult's social network as measured at T1 (O.R. = .71, $p = .01$). Compared to the likelihood of moving twice, the likelihood of moving three or more times is increased by higher adaptive behavior (O.R. = 1.19, $p = .04$).

Discussion

The present study addressed critical gaps in the literature by examining residential transitions among adults with intellectual disability over a 10 year period and residential transitions among a subsample of adults with Down syndrome over a 20 year period using data from a prospective, longitudinal study. Adults were living in a variety of settings, ranging from the homes of siblings and foster parents to independent apartments and nursing homes. Several characteristics of the adults with intellectual disability differed across settings, most notably adaptive behavior and history of residential transitions, while other characteristics such as age, type of disability and behavior problems were less predictive of residential placement. The number of moves over the course of the study varied widely, with critical links to earlier family dynamics, social relationships, and health and adaptive behavior. First, the residential settings of participants will be discussed, followed by a discussion of differences across these settings. Next, findings related to the number and antecedents of residential transitions will be reviewed.

The first aim was to describe the residential settings of adults with intellectual disability. After a period of 10 years, the majority of adults with intellectual disability were living with relatives, primarily parents. Adults with Down syndrome were not more likely than their peers with intellectual disability to live with relatives after 10 years. Some researchers have demonstrated a Down syndrome advantage in the subjective experience of parents of children with intellectual and developmental disabilities (Hodapp, Ly, Fidler, & Ricci, 2001). The present findings do not support the notion that adults with Down syndrome are more likely than adults with other intellectual disabilities to continue living with relatives. After 20 years, many of the adults with Down syndrome in this sample remained in the family home. Since the sample for Part 2 includes only adults with Down syndrome, it was not possible to compare the likelihood of living with relatives by type of disability.

Aging parents may have employed a variety of strategies to allow their child with intellectual disability to “age in place” and continue living in the family home (Jokinen et al., 2012). Public expenditures are catered toward out-of-home placements (Braddock, 2002), resulting in a dearth of evidence-based practices for in-home supports (Seltzer & Krauss, 2001). Future work should identify the supports and resources families used to retain their aging child in the family home. Beyond outcomes for the adult with intellectual disability, additional research is needed on the impact of continued caregiving on the well-being of parents in late life. This is an understudied area of research, although the existing literature suggests that continued caregiving may be both challenging and gratifying to aging parents (Seltzer, Floyd, Song, Greenberg, & Hong, 2011).

Alternatively, the number of adults living in the family home in mid- to late-adulthood may reflect unmet service needs. The need for residential services exceeded the receipt of such services in a sample of adults with intellectual disability and their aging mothers (Smith, 1997). As individuals with intellectual disability are living longer, the demand for residential services has increased (Lakin et al., 2003). The growing demand for services has led to longer wait times and increased pressure on families (Braddock, 2002; Jokinen et al., 2012). In 2011, an estimated 73,106 individuals with intellectual disability across 41 states were on waiting lists for residential services (Larson et al., 2013). The demand for residential services far outweighed the capacity to provide such services in most states. Overall, states would need to expand their current system by 17% to accommodate those individuals on current wait lists, with some states requiring expansions over 200% (Larson et al., 2013). Although several states have wait list reduction initiatives underway, additional funding and flexibility in current programs, such as the Home and Community Based Waiver and other Medicaid waivers, may be needed (Braddock, 2002).

At the end of 10 years, only a few adults with intellectual disability lived with their adult siblings. After a twenty-year period, half of the adults with Down syndrome in family settings lived with their adult siblings. This pattern highlights the increasingly important role siblings play in caring for adults with intellectual disability later in life. Due to the design of this study, it is not clear whether adults with Down syndrome are more likely to live with their siblings after an extended period of time than adults with other intellectual disabilities. Adult siblings of individuals with Down syndrome report closer sibling relationships than adult siblings of individuals with other intellectual disabilities (Hodapp & Urbano, 2007).

Future research should examine whether siblings of adults with Down syndrome are more likely to live with their brother or sister. The majority of the caregivers in this study were sisters, supporting previous work on the gendered nature of the sibling relationship. Sisters are more involved in the care of their sibling with intellectual disability (Orsmond & Seltzer, 2000) and more likely to expect their sibling with intellectual disability to eventually live with them (Krauss, Seltzer, Gordon, & Friedman, 1996).

Siblings and their families may experience difficulties navigating the disability service system. There is a lack of public policies that support siblings of individuals with intellectual disability in the United States (Arnold, Keller, & Kramer, 2012). Federal programs designed to support family caregivers, such as the National Family Support Program and the Lifespan Family Care Act, should explicitly include siblings in their definition of family caregivers and address their unique needs. Sibling caregivers may face multiple role and responsibilities in midlife, as they care for their sibling with intellectual disability as well as partners and children in many cases. Future research should consider the perspectives and experiences of brothers and sisters who care for their adult sibling with intellectual disability.

Most adults with intellectual disability and Down syndrome not living with relatives lived in community settings, such as group homes or shared apartments with full-time supervision. Few adults were living independently. These findings are consistent with Stancliffe et al. (2012), who reported only 14% of adults with intellectual disability and 7% of adults with Down syndrome lived in their own home. Adults with Down syndrome in this sample were not less likely to move into independent living settings than their peers with intellectual disability after a 10 year period, nor were they more likely to remain in the family home. These findings stand in contrast with those reported by Stancliffe and colleagues. The limited sample size of the present study may have masked these group differences, however.

A minority of adults with intellectual disability and adults with Down syndrome were placed in nursing home or hospital settings. Age-related declines may prompt caregivers to transfer their loved ones with intellectual disability to alternative settings due to medical necessity and safety management issues (Patti, Amble, & Flory, 2010). As individuals with intellectual disability are living longer, they become prone to the same age-related and chronic diseases as the general population (Jenkins, 2005). Rates of cancer, cardiovascular and respiratory disease and obesity, for instance, are on the rise in this population (Pitetti & Campbell, 1991), resulting in a greater need for palliative and hospice services (Gilbert, Wilkinson, & Crudgington, 2007). For adults with Down syndrome in particular, the onset of dementia may necessitate placement in a nursing home or hospital setting. Future research should examine characteristics of the environment of nursing homes, as they may relate to adaptive behavior, health and other outcomes for adults with intellectual disability (Heller, Miller, & Factor, 1998).

This study compared residential settings on characteristics of the adults with intellectual disability and their families, measured at both the start and the end of the study. With the exception of placement in nursing home or hospital settings, the age of the adult with intellectual disability or Down syndrome did not factor into his or her residential placement.

The most striking differences across residential groups related to adaptive behavior. In both samples, adults living in semi- or fully-independent settings showed higher levels of adaptive behavior. This finding is not surprising, given that adults with greater daily living skills may self-select into independent settings. This indeed appeared to be the case for adults with intellectual disability: adults who moved into independent settings displayed advantages in adaptive behavior at the start of the study, 10 years prior. For adults with Down syndrome, however, the self-selection into independent settings over the course of 20 years was less evident. Those who moved into independent settings did not show earlier advantages in self-care skills over adults who lived with relatives or in nursing home/hospital settings. These findings suggest that semi- or fully-independent living settings may be feasible for adults with Down syndrome with a broad range of self-care skills. Service providers should not restrict the residential options for adults with lower functional skills, following the results of this study.

Certain residential settings appeared to promote or maintain adaptive skills over the course of the study. Among adults with intellectual disability, those who moved into community settings showed greater improvement in adaptive behavior over 10 years than did adults living with relatives. Adults living outside the home may have more opportunities to perform activities of daily living independently. In addition, attention and support from staff members may promote self-care skills among residents (Jones et al., 2001). Over the course of 20 years, the adults with Down syndrome living in semi- or fully-independent settings showed the lowest declines in adaptive behavior. Taken together, the results suggest that residential settings with more opportunities to exercise self-care skills may help adults promote or maintain adaptive skills. Individuals who engage in meaningful, age-appropriate, activities in their place of residence show significantly higher rates of adaptive behavior development and maintenance (Mansell, Elliot, Beadle-Brown, Ashman, & Macdonald, 2002). Additional staff training may be required to encourage these opportunities in community residences.

Adults living with relatives demonstrated slight advantages in health. Adults with intellectual disability living with parents and siblings tended to have better overall health than adults living in community settings. This difference was present at the start of the study as well, however, suggesting that healthier adults tended to remain in the family home. This notion is also supported by the finding that better health at the start of the study decreased the likelihood of moving once. By the end of 20 years, adults with Down syndrome living with relatives had the highest health ratings and lowest declines in health. The direction of effects for this subgroup were less clear, however, since adults living with relatives did not show pre-existing advantages in health compared to their peers. It is possible the method of measuring health in this study did not capture important group differences and change over time. Future research should consider residential group differences in multiple domains of health and rely on a variety of reporters, including the adults with intellectual disability themselves.

No significant differences in behavior problems were observed across residential groups. This finding held true for externalized, internalized and asocial behaviors individually. The lack of differences in maladaptive behavior between adults with intellectual disability in

family and community settings is surprising. Problematic behaviors often motivate families to seek community placements for their relative with intellectual disability (Bromley & Blacher, 1991). The adults in this sample demonstrated relatively low levels of behavior problems, however, which may have limited the ability to observe group differences.

Adults with Down syndrome living in nursing home or hospital settings showed the highest rates of dementia, which is in line with reports that the majority of adults with dementia in the general population receive care in a nursing home (Mitchell, Teno, Intrator, Feng, & Mor, 2007). The declines in health and adaptive behavior observed in this group may be in part attributed to dementia-related declines. Adults with dementia were also living in family, community, and semi-independent settings at the end of the study, however. Future work should explore the strategies parents and siblings use to allow their family member with Down syndrome and dementia to age in place. Proactive modifications to the home environment may reduce problematic issues such as wandering and mobility constraints and allow adults with Down syndrome and dementia to remain in the familiar family home (Reed & Tilly, 2008). Within community settings, additional training for support staff may result in better outcomes for their residents with dementia and intellectual disability. Staff members who are familiar with the unique needs of their residents can more readily identify and assess symptoms and reduce levels of anxiety and behavioral issues (Tilly, 2008).

The number of moves over the course of the study period differed across settings. Adults with intellectual disability and Down syndrome living with relatives experienced significantly fewer transitions. With few exceptions, most adults with intellectual disability living with relatives after 10 years had not moved out of the family home. By the end of 20 years, only half of adults with Down syndrome in family settings remained with their parents and the remainder experienced relocations to the homes of adult siblings. Adults with intellectual disability and Down syndrome living outside of the home experienced more transitions, which is consistent with Krauss and Erickson (1988), who reported that adults with intellectual disability in community settings experienced higher residential transitions than adults in institutional or family settings. Community-based environments have been found to support and enhance self-determination (Wehmeyer & Bolding, 2001), which may encourage adults who are dissatisfied with their current living arrangement to seek alternative placements, resulting in a greater number of moves over time. Alternatively, difficulties with community-based settings, such as staff turnover and instability of agency funding, may have contributed to multiple moves for some residents. These factors were beyond the scope of the present study but should be examined in future research.

The number of moves experienced varied greatly, with some adults experiencing up to 11 relocations. On average, adults with intellectual disability experienced fewer than one transition after 10 years while adults with Down syndrome experienced nearly two transitions after 20 years on average. Recurrent relocations may reflect instability in caregiving relationships or problems with social adjustment in community residences. Transitions have been associated with emotional and behavior problems for adults with intellectual disability (Hamilton et al., 2005). Conversely, multiple transitions may imply self-determination among adults with intellectual disability. It may be the case that adults who are dissatisfied with their placements seek alternative residences. Future work should

focus more closely on the subset of adults with intellectual disability and Down syndrome who experience chronic relocations to identify potential causes and consequences. The age at which adults first moved out of the parental home also varied widely. While some moved out during a more typical young adult “launching” phase, others did not move until later in life. Reasons for relocation likely differed during each of these life phases, a topic which future research should address.

The number of transitions experienced over the course of the study related to early characteristics of the adults with intellectual disability and their families. A diagnosis of Down syndrome did not increase the likelihood of moving once, twice, or three or more times over the course of 10 years. This finding runs counter to the reports of Patti et al. (2005), which state that adults with Down syndrome are at higher risk of experiencing transitions relative to age-matched peers with intellectual disability. It is possible the duration of Part 1 of the study was insufficient to capture group differences, however. Alternatively, differences by diagnosis may have been explained by other family and personal characteristics in this study.

Adults with intellectual disability with lower health and adaptive behavior were more likely to move out of the home over the course of 10 years. This finding is consistent with previous work demonstrating the role of declining health in prompting out-of-home placements (Jokinen et al., 2012). Lower overall maternal health was likewise associated with relocation. This finding adds to the existing literature by revealing that poor maternal health is a risk factor for recurrent transitions specifically, not just one or two relocations. Poor physical health may prevent some mothers from providing the family involvement that is critical to adults' adjustment to relocation (Heller et al., 2002), preventing successful social integration. Health and adaptive behavior were not predictive of the number of transitions experienced by adults with Down syndrome over the course of 20 years. This pattern of findings may point to the normative experience of moving out of the parental home by late adulthood. By age 50, for example, most adults with Down syndrome may move out of the home regardless of the health of themselves or their mothers.

Older adults with intellectual disability and Down syndrome experienced more transitions over the study period, which is consistent with extant literature (Essex et al., 1997). Family income uniquely impacted the number of transitions among adults with Down syndrome over 20 years. Adults with lower levels of family income were at higher risk of relocating three or more times. This finding is consistent with the broader literature, which identifies socioeconomic status as a risk factor for social instability in the general population (Jelleyman & Spencer, 2008). Particular attention should be paid to the residential transitions of this subgroup of families with fewer resources.

Adults with intellectual disability and Down syndrome with more conflictual relationships were more likely to experience recurrent transitions. These findings are consistent with the notion that family relationships continue to influence the well-being of individuals with intellectual disability living outside the home (Alborz, 2003; Seltzer et al., 2001). Conflict may reduce the family's level of involvement in the adult's life in the community, which has been found to benefit adjustment to new residential settings (Schalock & Lilley, 1986).

Future research should consider additional mechanisms through which family relationships impact residential transitions for adults with intellectual disability. Conversely, longstanding social connections established while living in the family home appeared to protect adults from relocating more than once. Support from social networks may benefit adults with intellectual disability and Down syndrome by facilitating adaptation to new environments (Jacobson & Kropf, 1993; Jokinen et al., 2012). This finding extends our understanding of the importance and role of social networks for adults with intellectual disability.

This study has several limitations. First, the sample is of Caucasian descent, thereby limiting the generalizability to other racial or ethnic groups. Although we captured the number of residential transitions over the 20 year period, this study did not examine the reasons for relocations. Changes in adult and family characteristics were also not captured. Declining health, for instance, may have prompted relocations over the course of the study. This study may have lacked sufficient power to detect differences across residential groups, given the small group sizes. The number of adults living in nursing home or hospital settings was particularly small, therefore the present results should be interpreted with caution since this small group may not be representative of adults in nursing home/hospital settings more broadly. The findings from the attrition analyses suggest the samples used in these analyses may be biased toward families with higher education and income, thereby limiting the generalizability to other socioeconomic groups. Since socioeconomic status was a risk factor for recurrent transitions, future research should make explicit efforts to capture the experiences of adults with intellectual disability from low income families. Lastly, this study relied on caregiver report and did not incorporate the perspectives of the adults with intellectual disability themselves. Consideration of their residential preferences would elucidate our understanding of reasons for residential transitions.

Despite these limitations, this study contributes to our understanding of outcomes for adults with Down syndrome across different residential settings. Understanding the typology of individuals within each residential setting will help practitioners identify and implement best practices, thereby improving quality of living outcomes among individuals with intellectual disability. Unlike previous work in this area, the analyses employed data from a prospective, longitudinal study. This data provided a unique opportunity to examine antecedents of relocations over the life course. It also identified risk and protective factors for the experience of recurrent residential transitions during adulthood. Further investigation of residential discontinuity is needed to better understand ways families and service providers can foster positive outcomes among adults with intellectual disability.

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Table 1
Description of the Samples for the Original Project and Parts 1 and 2 of the Present Study

	Original Sample (Time 1)	Sample Part 1 (Time 1-Time 8)	Sample Part 2 (Time 1-Time 9)
Intellectual Disability	292	229	0
Down Syndrome	169	133	75 ^a
Total	461	362	75 ^a

^a All but four participants were included in the sample for Part 1

Table 2

Descriptive Statistics at T1

T1 Characteristics	Sample Part 1 (N=362)				Sample Part 2 (N=75)			
	M	SD	Min.	Max.	M	SD	Min.	Max.
Family								
Family income (median)	\$20,000-29,999		<\$5,000	\$50,000+	\$20,000-29,999		<\$5,000	\$50,000+
Family size	5.67	1.98	2	11	6.27	1.94	3	11
Family conflict	1.52	1.52	0	8	1.21	1.31	0	5
Maternal health ^a	1.99	0.76	0	3	2.16	0.75	0	3
Adult with intellectual disability/DS								
Age	33.33	7.26	15	58	28.90	5.87	15	43
Adaptive behavior	21.15	7.61	0	34	23.23	5.99	5.00	33.00
Health ^a	3.35	0.71	1	4	3.51	0.62	2	4
Social support network								
Network size ^b	6.88	2.62	1	10	7.04	2.65	2.00	10.00
Age of contacts	49.39	9.77	27.56	78.33	47.42	9.01	31.38	74.00
Years known	25.88	7.46	8.75	52.60	23.37	5.54	12.10	35.00
Geographic proximity ^c	0.89	0.19	0.14	2.20	0.86	0.25	0.20	2.20
Frequency of contact ^d	5.46	0.92	2.89	7.00	5.42	0.89	3.50	7.00
Inclusion in mother's network ^e	0.52	0.26	0	1	0.56	0.24	0.00	0.90

^a 1 = *very poor/poor*, 2 = *fair*, 3 = *good*, 4 = *excellent*

^b Number of contact listed out of 10

^c Proportion of contacts within 1 hour drive

^d 0 = *never* to 7 = *daily*

^e Proportion of contacts included in mother's network

Table 3
Comparison of T1 and T8 Adult Outcomes by Residential Settings at T8: Estimated Marginal Means Controlling for Age (N=362)

T8 Variables	A. With Relatives (n=239)			B. Community Living (n=88)			C. Semi- or Fully- Independent Living (n=22)			D. Nursing Home or Hospital (n=13)		
	M	SE		M	SE		M	SE		M	SE	F group (df=3)
Adaptive behavior												
T1	21.48 ^{cd}	0.48		19.67 ^c	0.79		27.18 ^{abd}	1.58		14.96 ^{ac}	2.08	9.04***
T8	21.64 ^{cd}	0.50		21.60 ^{cd}	0.82		26.63 ^{abd}	1.65		14.00 ^{abc}	2.18	7.04***
Change (T8-T1)	0.16 ^b	0.34		1.93 ^a	0.56		-0.54	1.13		-0.96	1.49	3.09*
% SD Change	2.10%			25.36%			7.10%			12.61%		
Health												
T1	3.42	0.05		3.21	0.07		3.05	0.15		3.65	0.20	4.06**
T8	3.21	0.05		2.98	0.08		2.79	0.17		2.78	0.22	3.91**
Change (T8-T1)	-0.21 ^d	0.05		-0.23	0.09		-0.27	0.18		-0.86 ^a	0.23	2.47 [†]
% SD Change	-29.58%			-32.39%			-38.03%			-121.13%		
Behavior Problems												
T2	104.33	0.43		105.61	0.70		104.58	1.41		108.61	1.86	2.24 [†]
T8	104.04	0.34		104.44	0.55		104.16	1.11		106.80	1.46	1.19
Change (T8-T1)	-0.30	0.44		-1.17	0.72		-0.42	1.45		-1.80	1.92	0.50
% SD Change	-4.54%			-17.70%			-6.35%			-27.23%		
Number of moves	0.16 ^{bcd}	0.06		1.80 ^a	0.10		2.40 ^a	0.21		2.21 ^a	0.27	96.94***

^aDiffers from With Relatives,

^bDiffers from Community Living,

^cDiffers from Semi or Fully Independent Living,

^dDiffers from Nursing Home or Hospital,

[†]p < .10,

* p < .05,

** p < .01

Table 4
T1 Predictors of Residential Transitions from T1 to T8 (N=362)

T1 Variable	1 Move (n=75)		2 Moves (n=38)		3+ Moves (n=31)	
	b (SE)	OR	b (SE)	OR	b (SE)	OR
Intercept	2.15 (1.19)		-0.71 (1.61)		-3.41 (1.85)	
Family						
Family income	-0.06 (0.15)	0.94	-0.18 (0.20)	0.84	-0.29 (0.23)	0.75
Family size	-0.08 (0.08)	0.92	0.05 (0.09)	1.05	-0.09 (0.11)	0.91
Family conflict	0.07 (0.09)	1.07	0.24 (0.11)	1.27*	0.23 (0.14)	1.26 [†]
Maternal health ^a	-0.10 (0.20)	0.90	-0.22 (0.26)	0.80	-0.64 (0.29)	0.53*
Adult with intellectual disability						
Age	0.02 (0.03)	1.02	0.02 (0.03)	1.02	0.10 (0.04)	1.11**
Down syndrome (vs. other)	0.24 (0.31)	1.28	0.36 (0.40)	1.43	0.51 (0.45)	1.67
Gender (male)	0.05 (0.28)	1.05	-0.06 (0.37)	0.94	-0.68 (0.42)	0.51 [†]
ADL	-0.04 (0.02)	0.96*	0.02 (0.03)	1.02	0.04 (0.03)	1.04
Health ^a	-0.50 (0.21)	0.60**	-0.19 (0.28)	0.82	0.12 (0.31)	1.13
Social support network						
Years known	-0.04 (0.03)	0.96	-0.08 (0.03)	0.92**	-0.07 (0.03)	0.93*

Note: reference category is 0 Moves (n=218)

^a 1 = very poor/poor, 2 = fair, 3 = good, 4 = excellent

[†] p < .10,

* p < .05,

** p < .01

Table 5
Comparison of T1 and T9 Adult Outcomes by Residential Settings at T9: Estimated Marginal Means Controlling for Age (N=75)

T9 Variables	A. With Relatives (n=26)			B. Community Living (n=36)			C. Semi- or Fully- Independent Living (n=9)			D. Nursing Home or Hospital (n=4)		
	M	SE		M	SE		M	SE		M	SE	F group (df=3)
Adaptive behavior												
T1	23.34	1.15		21.81 ^c	0.97		28.00 ^b	1.93		24.48	3.11	2.80 [*]
T9	19.28 ^{cd}	1.44		16.51 ^c	1.21		27.29 ^{abd}	2.42		5.53 ^{ac}	3.90	9.20 ^{***}
Change (T9-T1)	-4.06 ^d	1.23		-5.30 ^d	1.03		-0.71 ^d	2.06		-19.05 ^{abc}	3.31	7.72 ^{***}
% SD Change	-67.78%			-88.48%			-11.85%			-318.03%		
Health¹												
T1	3.55	0.13		3.47	0.11		3.46	0.21		3.67	0.34	0.18
T9	3.02	0.13		2.63	0.11		2.93	0.21		2.11	0.34	3.14 [*]
Change (T9-T1)	-0.53	0.14		-0.84	0.12		-0.54	0.24		-1.56	0.38	2.65 [†]
% SD Change	-85.48%			-135.48%			-87.10%			-251.61%		
Behavior Problems												
T2	102.46	0.91		103.28	0.76		104.43	1.52		104.52	2.45	0.52
T9	102.34	0.66		102.80	0.55		100.46	1.10		102.61	1.77	1.21
Change (T9-T2)	-0.12	1.05		-0.49	0.88		-3.97	1.76		-1.91	2.83	1.29
% SD Change	-2.61%			-10.68%			-86.49%			-41.61%		
Number of moves	0.65 ^{bc}	0.28		2.20 ^a	0.23		2.44 ^a	0.46		1.71	0.73	7.31 ^{***}
Dementia	0.12 ^d	0.08		0.28	0.06		0.31	0.13		0.78 ^a	0.20	3.32 [*]

^aDiffers from With Relatives,

^bDiffers from Community Living,

^cDiffers from Semi or Fully Independent Living,

^dDiffers from Nursing Home or Hospital,

¹ 1 = very poor/poor, 2 = fair, 3 = good, 4 = excellent,

[†] p < .10,

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

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Table 6
T1 Predictors of Residential Transitions from T1 to T9 (N=75)

T1 Variable	1 Move (n=27)		2 Moves (n=15)		3+ Moves (n=17)	
	b (SE)	OR	b (SE)	OR	b (SE)	OR
Intercept	-2.94 (3.79)		2.71 (4.35)		-0.96 (4.51)	
Family						
Family income (z-score)	-0.75 (0.51)	0.47	-1.19 (0.65) [†]	0.30	-1.52 (0.67) [*]	0.22
Family size	0.01 (0.17)	1.01	-0.15 (0.23)	0.86	0.03 (0.22)	1.03
Family conflict	0.60 (0.45)	1.83	1.03 (0.49) [*]	2.81	1.08 (0.48) [*]	2.95
Maternal health ^a	0.22 (0.52)	1.25	0.97 (0.74)	2.64	0.07 (0.68)	1.07
Adult with DS						
Age	0.14 (0.11)	1.15	0.26 (0.13) [*]	1.30	0.19 (0.13)	1.21
Gender (male)	0.13 (0.82)	1.13	1.23 (1.06)	3.42	-0.04 (0.96)	0.96
Adaptive behavior	-0.08 (0.07)	0.93	-0.10 (0.08)	0.91	0.08 (0.10)	1.08
Health ^a	0.41 (0.69)	1.51	-0.58 (0.86)	0.56	-0.57 (0.77)	0.57
Social support network						
Years known	-0.03 (0.11)	0.97	-0.38 (0.15) ^{**}	0.69	-0.23 (0.15)	0.80

Note: reference category is 0 Moves (n=16)

^a 1 = very poor/poor, 2 = fair, 3 = good, 4 = excellent

[†] p < .10,

^{*} p < .05,

^{**} p < .01