

AN EVALUATION OF THE JACKSONVILLE DEVELOPMENTAL CENTER CLOSURE

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EXECUTIVE SUMMARY

In January 2012, Illinois Governor Pat Quinn announced his rebalancing initiative in an effort to move away from institutionally-based services toward community-based supports for people with IDD. The goal was to close four State Operated Developmental Centers (SODCs) and transition residents to community settings; Jacksonville Developmental Center (JDC) was one of the facilities slated to close (Illinois Government News Network, 2012). The Illinois Department of Public Health contracted the Institute on Disability and Human Development (IDHD) at the University of Illinois at Chicago (UIC) to conduct an evaluation of the JDC closure.

The JDC evaluation included four phases. In Phase I, surveys were sent to guardians of all former JDC residents who were involved in the closure to understand family/guardian perspectives on the closure and transition of their relative; 65 individuals responded. Eighty-eight percent (n = 57) of the survey respondents were family members (parents, siblings, aunts/uncles, nieces/nephews, or cousins), while the remaining 12% (n = 8) were state guardians. In Phase II, interviews/focus groups were conducted with 53 individuals who had a professional role in the closure and transition process to gain their insight. Phase III included face-to-face interviews with 15 former JDC residents that asked about their satisfaction with the transition process and their current living situation. Phase IV will include an analyses of the one year post transition outcome data. This executive summary reflects data from Phases I-III. Results from Phase IV are forthcoming.

Satisfaction with JDC Closure and New Setting

- Initially, the overwhelming majority of the Family/Guardian Survey respondents (83%, n = 54) indicated dissatisfaction with the decision to close JDC. Of the respondents who were dissatisfied, the reasons they provided for being dissatisfied included: having already gone through a previous SODC closure, believing that their relative/ward required more support than the community could provide, their relative/ward had a previous failed community placement, fear if the community provider would still be there for the long term, and worry that the new provider would not continue to serve their relative/ward because of behavior issues. This feeling of dissatisfaction did not last. Almost half of the survey respondents (46%; n = 29) felt more positive towards the decision to close JDC one year after closure. A greater percentage of the survey respondents currently felt that their relative/ward would benefit from a move to the community, when compared to how they initially felt (33.3% vs. 54.8% respectively).
- Almost all of the survey respondents (92%, n = 58) felt satisfied with their relative's new setting. An overwhelming majority (86.7%, 52 out of 60) of the

families/guardians felt their relative was about the same or better when compared to when they lived at JDC. The new settings were located in safe neighborhoods, and respondents felt necessary services were available to their relative/ward in the community. JDC residents reported increased opportunities to participate in activities (including working in their garden, watching movies, going to basketball games, shopping) after moving to the community. They also expressed satisfaction with particular aspects of their new home including increased freedom, their neighborhood, their own rooms, and food options. There was increased opportunity for learning new skills such as budgeting money, learning to cook and using the computer. Former JDC residents liked the staff at their new setting; however some stated that they missed their friends at JDC but became friends with the people they now live with.

Opinions on Using a Third Party for Person Centered Planning

- Stakeholder opinions differed regarding the use of a third party entity to conduct pre-transition assessments. There was some duplication in efforts between JDC staff and the Community Resource Associates (CRA). The use of CRA led some JDC staff to feel insulted because there was a perception that CRA was “telling [JDC staff] how to do what [they] have been doing.” Several stakeholders thought the use of a third party entity to lead the PCPs was beneficial because it added objectivity to the process. Others felt that the third party complemented the assessments already conducted by JDC staff. Some JDC staff members were not able to participate in the person centered planning (PCP) process and to provide some critical historical information because of attrition.
- PCP was beneficial but there was confusion about its purpose. The goals of individuals were captured through the PCP process. However, some stakeholders felt that the use of CRA to conduct PCPs was not beneficial because of their lack of familiarity with the individual and that CRA had predetermined philosophies about community-based living. Some stakeholders felt the philosophy behind PCPs might be confusing to some elderly parents/guardians and that there should be a greater focus on medical and health needs of the individual.

Communication Between Key Players

- Lack of communication and poor communication between stakeholders, relatives/guardians, and residents of JDC was a common theme across interview and survey respondents. Family members and guardians who perceived that they did not receive adequate information prior to making a choice of a residential setting were more likely to report being “very dissatisfied” with the closure process. Complicating this finding was that families/guardians reported receiving conflicting information from multiple sources and weren’t sure from whom to get accurate information. There was also confusion amongst the stakeholders as to who was in charge of the closure. For example, six different individuals or entities were identified during the stakeholder interviews as being “in charge.” Friends, television and news crews were mentioned by former JDC residents as sources where they first heard about the JDC closure.
- The JDC staff played an integral role with both stakeholders and families/guardians during the closure process. Communication with the JDC staff was inconsistent and/or poor and led some to feel disgruntled. Some respondents felt that JDC staff did not have sufficient resources nor proper leadership (there were at least three different JDC directors during the closure) to support the transition. The lack of communication contributed to some JDC staff not knowing when some residents were moving.

The JDC Closure Process

- Approximately half (52%, n = 34) of survey respondents indicated that the closure timeline was too short/rushed. The perception of feeling rushed was also held by key stakeholders. Community agencies stated that they needed more time to build, license and certify new homes as well as hire and train staff. Because some family members or guardians refused to accept that JDC would actually close, they did not get involved in the transition process until right before the end.
- Stakeholders indicated that provider meetings needed philosophical and structural improvements. Early on the initial meetings with providers were described as an “auction” where providers publicly displayed their hands to indicate their willingness/ability to support the individual whose information was presented. This process was later amended to encompass a silent ballot where providers indicated their willingness to accept the individual on a sheet of paper. Stakeholders were pleasantly surprised by the number of providers in Illinois that were willing to participate in the Active Community Care Transition (ACCT) process (since its implementation, the number doubled from 20 to over 40). However, some stakeholders indicated that families that did not like the ACCT process and would circumvent it by working directly with a provider.

- The amount and quality of information received about the JDC residents was a disappointment to some stakeholders. Community agencies reported that there was some missing or outdated information in former JDC resident records. There were allegations of sabotage of individual records and behavioral plan monitoring logs. Some stakeholders felt that CRA was too idealistic about the abilities and needs of individuals; conversely information provided by JDC staff was embellished (e.g., behavioral issues were exaggerated to deter providers from moving forward with the transition). When the JDC residents moved into their new home, some arrived without necessary documentation (e.g., Medicaid cards, state IDs, social security cards, etc.). Some agency staff felt the existing behavioral plans were not appropriate to community living and had to be significantly altered.

The New Home

- There was a perception held by many family members, guardians, and stakeholders that there was a limited choice of new settings for the former JDC residents. Some stakeholders indicated that because some families/guardians waited till the end of the transition process, their family members had to move to another SODC on a temporary basis until their permanent home was ready for them. There was a sense that there was a lack of guidance for family members and guardians to assist them in finding a new home for the family members. Former JDC residents felt their choices for a new home were limited because their desires were overshadowed by other people's (particularly their mother's) opinions regarding of what setting was best for them and the mother's choice was ultimately where they moved to living.
- Only 44% (n = 27) of survey respondents indicated their family member/ward visited their new residence before moving; less than 17% (n = 11) indicated they had an overnight visit. Respondents who indicated that their relative/ward did not visit any homes prior to the move were more likely to report being dissatisfied with the closure process. Possible explanations by stakeholders as to why former JDC residents did not visit their new home included: a belief the visit could confuse the JDC resident; the new home was still under construction; and the families/guardians did not start the PCP process until right before the closure. However, when the family members or guardians did visit the new home they "were really surprised [at] how nice it was... They said that [their relative] would really enjoy it. The one thing that they liked is that he had a lot of room to move around" and that they "never thought that [the JDC resident] would live in a house, in a neighborhood". Former JDC residents who did go on pre-transition visits reported seeing the physical home, but not meeting the staff.
- Stakeholders indicated that moving day felt hectic and disorganized as JDC residents moved to their new home. Safety was the number one priority across all stakeholders. Oftentimes when a JDC residents moved, they were not accompanied

by the direct support professional staff from JDC who knew them best. Stakeholders indicated that JDC residents were typically dropped off by support staff (such as transportation personnel). Also, providers noted that the drivers had multiple stops to make and, thus, dropped the individual off and then quickly moved on to the next stop. Additionally, there were allegations that JDC residents often arrived at the new home with very few belongings, usually in trash bags. Some individuals, agency staff reported, arrived with clothing that was labeled with another person's initials, with little money (\$30-\$40 at most), and the money they had in savings at the SODC took months to arrive at the new home. Many agencies went out of their way to make the individual's transition go smoothly and to ensure that the individuals felt welcome in their new home, such as providing a birthday cake when one JDC resident moved in on his birthday.

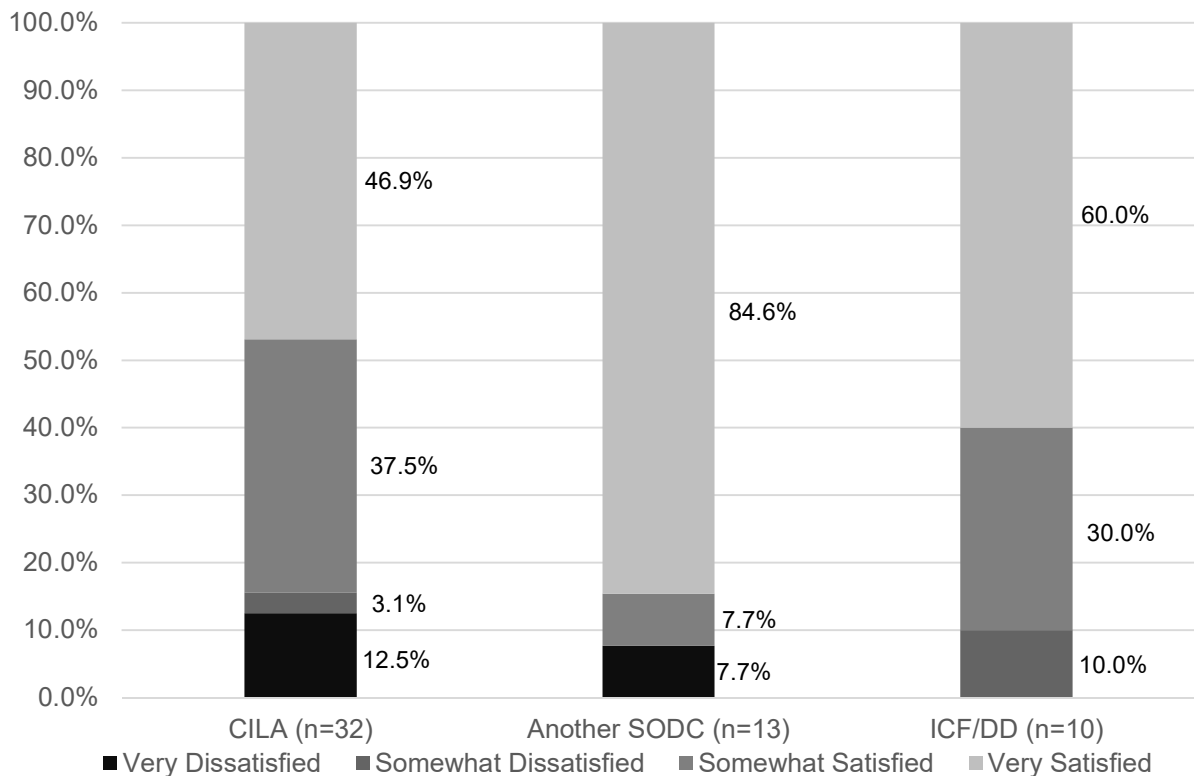
- Many stakeholders noted confusion regarding the post-transition follow up. There was confusion for both agency staff and former JDC residents because there were multiple entities coming in and out of provider agencies to conduct follow-up visits.

Barriers to Transition

- There were many systemic barriers that slowed the pace of the closure process. Some stakeholders indicated the flexibility of individualized budgets and the enhanced, expedited rates allowed agencies to support individuals with complex medical and behavioral needs. However there was a sentiment amongst agencies that despite the enhanced rates, some providers were hesitant to make such a large capital investment (e.g., new homes and new vehicles). Many providers were worried that the rates would not remain steady for the long-term, and many indicated confusion over the process for filing for enhanced funding. Community direct support professional wages, stakeholders felt, were too low and resulted in high turnover rates. Many indicated a critical need for increased crisis services for individuals with challenging behaviors. Some stakeholders reported a lack of healthcare providers knowledgeable about IDD.

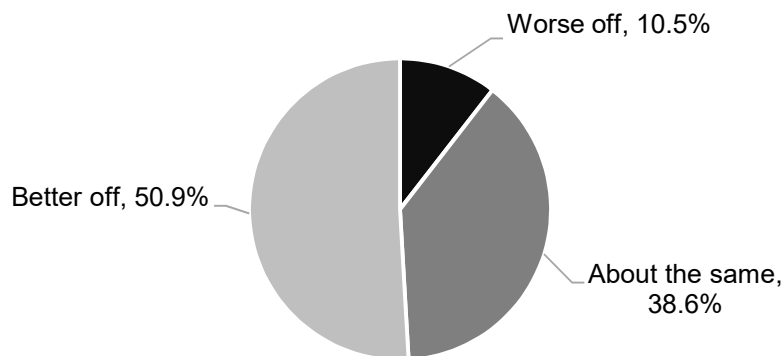
How satisfied are the survey respondents with the former JDC resident’s current living situation?

- Of family members whose relative transitioned to a CILA (n=32), the majority (84.4%) were either somewhat or very satisfied with the former JDC resident’s current living situation.



Is the former JDC resident better or worse off when compared to that person’s time at JDC?

- The majority of respondents (50.9%) who were a family member (n=57) of the former JDC resident stated that the former JDC resident was “better off” now.
 - Another 38.6% felt their relative was “about the same” compared to when they lived at JDC.



How many times did the former JDC residents who moved to a CILA (n=107) use the ER? Why did the former JDC resident have to go to the ER?

- Most (52.4%) did **not** use the ER within the first year since moving from JDC.
 - Nearly a quarter (27.1%) utilized the ER just once within the first year since moving from JDC.
- Reasons for ER use included: illness only (13.1%), injury only (11.2%), behavior only (3.7%), or “other” reasons (11.2%).
 - 8.4% utilized the ER for multiple reasons.
- Data was not available for a comparison group, so conclusions cannot be made about whether rates of ER utilization differed from other SODC residents.

How many times did former JDC residents who moved to a CILA (n=107) have police involvement? Why were police involved?

- The vast majority (85.0%) did **not** have police involvement within the first year since moving from JDC.
 - 7.5% had one police involvement.
- Reasons for police involvement included: aggression towards others only (3.7%), elopement only (2.8%), and “Other” reason only (0.9%)
 - 7.6% had multiple reasons for police involvement.
- Data was not available for a comparison group, so conclusions cannot be made about whether rates of police involvement differed from other SODC residents.

INTRODUCTION

Jacksonville Developmental Center (JDC) began operation in 1851 as the Illinois Central Hospital for the Insane; by 1893 the census was over 1,200 residents (Illinois Board of World's Fair Commissioners, 1893). In 1869, it was renamed the Illinois Central Hospital for the Insane and in 1910 was again renamed the Jacksonville State Hospital. In the 1970s the institution began serving individuals with developmental disabilities and was renamed to reflect this in 1974 to Jacksonville Mental Health and Developmental Center.

Like Illinois, many other states built institutions to provide board and care to the states' residents with disabilities. By 1967, the US institutional census peaked at over 195,000 people (Department of Health, Education and Welfare, 1972). Since then, the national institutional census had decreased by an average of 5% annually for 43 years. By 2011, 29,574 people were living in publicly funded and state run institutions across the US. By 2013, 12 states and the District of Columbia closed all state operated institutions for people with developmental disabilities (Braddock et al, 2013).

Illinois has also participated in institutional downsizing, closing nine State Operated Developmental Centers (SODCs) since 1982. Most recently, in 2004, Lincoln Developmental Center closed and Howe Developmental Center closed in 2010. In January 2012, Illinois Governor Pat Quinn announced his rebalancing initiative, called the Active Community Care Transition (ACCT) plan. The ACCT plan was implemented in an effort to move away from institutionally-based services toward community-based supports for people with IDD. The goal of the ACCT plan was to close four additional SODCs and transition residents to community settings; JDC was one of the facilities slated to close (Illinois Government News Network, 2012). At the time of announcement of the JDC closure, 185 residents were living there. Illinois operates seven other SODCs (Choate, Fox, Kiley, Ludeman, Mabley, Murray and Shapiro). Only Texas and New Jersey support more people than Illinois in these settings (Braddock et al., 2013).

Numerous studies have examined deinstitutionalization outcomes for individuals with intellectual and developmental disabilities (IDD) who have moved from institutions

to community-based settings (see Lakin, Larson, Kim, & Kim, 2011; and Heller, Schindler & Rizzolo, 2008). Through this body of research, it has been well-established that moving from institutional settings into smaller community-based ones leads to better outcomes for people with IDD (Kim, Larson, & Lakin, 1999; Larson & Lakin, 1989; Larson & Lakin, 2012). Similar studies have been conducted in Illinois to determine outcomes for individuals leaving State Operated Developmental Centers (SODCs) as a result of closure (Braddock, Heller & Zashin, 1984; Fujiura, Fitzsimons-Cova & Bruhn, 2002; Heller, Factor & Braddock, 1986) as well as to determine overall transition outcomes (Lulinski Norris, Rizzolo & Heller, 2012). In an effort to continue monitoring the outcomes of individuals who are transitioning out of Illinois SODCs, the Illinois Department of Public Health contracted the Institute on Disability and Human Development (IDHD) at the University of Illinois at Chicago (UIC) to conduct an evaluation of the JDC closure.

OBJECTIVES

The JDC evaluation includes four separate phases: Phase I) analysis of family/guardian perspectives on the closure and transition; Phase II) examination of stakeholders' experiences with the closure and transition process; Phase III) analysis of individuals' satisfaction with the process and current living situation; and Phase IV) examination of the outcomes for individuals who moved. The present report summarizes findings from Phases I-III. Results from Phase IV are forthcoming.

PHASE I: FAMILY/GUARDIAN SURVEY

METHODS

Phase I of the JDC closure evaluation consisted of a paper-based 66 question Family/Guardian Survey (see Appendix A). Information was collected regarding the following domains:

- Demographics of respondent and/or individual transitioned (age, gender, race/ethnicity, education level);
- Satisfaction with services at JDC and the decision to close JDC;
- Satisfaction with the transition and closure process;

- Satisfaction with the new placement and the services received there;
- Effects of relocation on visitation patterns; and
- Personal opinions of how the relative/ward is doing since transition and the impact closure had on the family.

Sixty-one questions were multiple choice, while five were open-ended questions related to the closure process as well as perceptions about services received at both JDC and the new residential setting. Survey materials (cover letter, survey, interview consent and a postage paid return envelope) were prepared by the research team at IDHD and mailed by the Division of Developmental Disabilities to all 180 guardians to ensure respondent confidentiality. Surveys received were anonymous unless the respondent indicated his/her name or the name of his/her relative/ward on the survey; however this information was not requested. The initial survey was sent in May of 2013, to which 32 individuals responded. A second mailing was completed in August of 2013 to which an additional 33 guardians responded for a total of 65 surveys yielding a 36% response rate which is consistent with similar paper-based Medicaid studies using mailed surveys (Gibson, Koepsell, Diehr, & Hale, 1999; U.S. Agency for Healthcare Research and Quality, 2001).

Upon receipt, surveys were coded and then entered into SPSS 22.0 for analysis. Answers to open-ended questions were entered into an Excel spreadsheet and coded by three members of the research team from which key themes were identified using a grounded theory approach which allows the objective consideration of data without predetermined hypotheses (Mertens, 2005).

SURVEY RESULTS

Demographics

Eighty-eight percent (n = 57) of survey respondents indicated they were family members (parents, siblings, aunts/uncles, nieces/nephews, or cousins) while the

remaining 12% were state guardians¹. It appears that family guardian respondents were over-represented in the survey; 68.5% of all former JDC residents had a family member as guardian, however this group makes up 88% of all survey respondents. In addition, it appears that state guardian respondents were under-represented; 26.4% of all former JDC residents had a public/state guardian, however they comprise 12.3% of survey respondents. Table 1 presents the relationship of the respondents to the mover.

Table 1: Respondent Relationship to Mover

(N = 65)

	n	%
Parent	31	47.7
Sibling	19	29.2
Public Guardian	8	12.3
Other (aunt, uncle, niece, nephew or cousin)	7	10.8

The mean respondent age was 67.4 years old (SD = 11.9 years). Table 2 (next page) presents additional guardian demographics.

¹ As the majority of respondents were relatives of former JDC residents, the terms 'relative' or 'family member' will be used throughout the remainder of this report in lieu of 'ward'.

Table 2: Family/Guardian Demographics

(N = 65)

	n	%
Age		
65 or older	36	55.4
Less than 65	27	41.5
No response	2	3.1
Gender		
Female	44	67.7
Male	21	32.3
Race/Ethnicity		
White	56	86.2
Black	6	9.2
Other	3	4.6
Education		
College graduate or more	27	41.6
Some college	19	29.2
High school or less	19	29.2

Respondents were also asked to provide demographic details about the individual who moved from JDC (see Table 3, next page). The average age of individuals who transitioned from JDC was 50.9 years (SD = 11.0) ranging in age from 26 to 75 years; this is consistent with the average age of all former JDC residents who moved out during the same time period which was 49.1 years. The majority of the individuals represented by a survey respondent were White males over age 50 (43.1%). White former JDC residents were over-represented by survey respondents; 52.8% of all former JDC residents were white while 83.1% of survey respondents indicated that their relative was white. Black former JDC residents were under-represented by survey respondents; 46.1% of all former JDC residents were black while only 9.2% of their guardians responded to the survey.

Thirty-seven percent of respondents indicated that their relative had lived at JDC for less than 10 years and an additional 37% lived at JDC between 11 and 20 years. Over a quarter (26%) had lived at JDC for over 20 years. Data for all former JDC residents was as such: 52.2% lived at JDC for ten years or less; 15.7% lived there for 11-20 years; and 32% lived there for over 20 years. It appears as though respondents over-represented the percentage of people who lived at JDC for 11-20 years.

In terms of mobility needs, 21.5% of individuals required mobility devices. Less than 10% required seating equipment, while less than 5% required communication devices.

Respondents (n=61) indicated that the majority of individuals (62.3%) came to JDC from another SODC. Eighteen percent came from a CILA, 9.8% from a family home, 8.2% from an ICF/DD, and 1.6% from a nursing home.

Table 3: Mover Demographics

(N = 65 unless indicated)

	n	%
Age		
50 or older	39	60.0
Less than 50	26	40.0
Gender		
Male	52	80.0
Female	13	20.0
Race		
White	54	83.1
Black	6	9.2
Other	5	7.6
Years at JDC (n=63)		
10 or less	24	38.1
11 to 20	24	38.1
21 or more	15	23.8
Equipment use		
Mobility	14	21.5
Seating	6	9.2
Communication	3	4.6
Residence prior to JDC (n = 61)		
Other SODC	38	62.3
CILA	11	18.0
Family Home	6	9.8
ICF/DD	5	8.2
SNF	1	1.6

Activities of Daily Living

Respondents were provided a list of 17 activities of daily living (ADLs) and were asked to indicate all the activities with which their relative required assistance. On average, the number of ADLs that the person with IDD required assistance with was

10.7 (SD = 4.4). One respondent said their relative did not require any assistance with ADLs, while nine reported that their relative required assistance with all 17 ADLs. Table 4 indicates the percentage of respondents who stated that their relative required assistance with that ADL.

Table 4: Activities of Daily Living That Require Assistance

N = 65 unless indicated

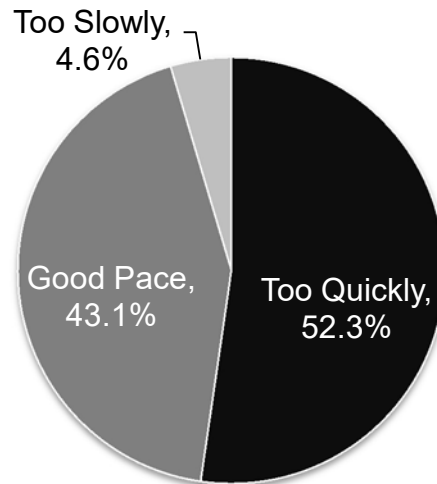
	n	%
Managing money	60	92.3
Managing medication	58	89.2
Preparing meals	53	81.5
Behavioral support	52	80.0
Shopping for groceries	47	72.3
Using a telephone	47	72.3
Doing heavy housework	47	72.3
Getting to places outside (n=64)	47	72.3
Communication	44	67.7
Bathing (n=64)	39	60.0
Dressing (n=64)	33	50.8
Doing light housework (n=64)	33	50.8
Toileting	32	49.2
Transferring	28	43.1
Getting outside	28	43.1
Eating	25	38.5
Walking	21	32.3

Almost all individuals (92%), guardians felt, required assistance with managing money. Eighty-nine percent needed assistance with managing medication, 82% with preparing meals, and 80% with behavioral support. Over 70% needed assistance with each of the following: shopping for groceries, using a telephone, doing heavy housework, and getting to places outside. Over two-thirds, guardians indicated, needed assistance with communication (68%) and 60% with bathing. Approximately half of the former residents needed help with dressing (51%), doing light housework (51%) and toileting (49%). Over 40% needed assistance with transferring and getting outside. Approximately a third needed assistance with eating (38%) and walking (32%).

Pre-Move Information and Visits

Respondents were asked how they felt about the pace of the closure process. Over 52% indicated that the pace went “too quickly”, 43.1% indicated it went at a “good pace” and 4.6% indicated it went “too slowly” (Figure 1).

Figure 1: Respondent perception of closure pace (N = 65)



Respondents were also asked whether they received timely updates on their relative’s transition process; 60% indicated that they had. The majority (61.5%) of respondents indicated that they had received information on other residential options and 53.8% felt that the information provided was adequate. Nearly 57% of respondents indicated that they had visited at least one agency prior to making a decision. Respondents indicated that 44.3% of their relatives visited their new home at least once prior to the move; 16.9% for an overnight stay (see Table 5, next page).

Table 5: Pre-move Process N = 65

	n	%
The respondent indicated that they...		
Received timely updates on relative's transition	39	60.0
Received any information on other residential options	40	61.5
Received adequate information on service providers	35	53.8
Respondents (n=62) indicated that they visited...		
At least one provider agency	37	59.7
Respondents indicated that their relative visited their new home...		
At least once (n = 61)	27	44.3
Short visit (for less than 3 hours) (n = 59)	21	35.6
Day visit (over 3 hours but not overnight) (n = 59)	16	27.1
Overnight or longer (n = 59)	11	20.3

Respondents were asked the following open-ended question: "How did you choose your relative's new home?"

Some respondents felt they had limited choice. Statements included:

"It was the only agency that contacted me - they seemed genuinely interested in serving my family."

"This was the first option presented to us. There were no options in the [city] area."

"Only choice I had. Started to change program very late - no time to really check it out."

Other respondents indicated they relied on input from DHS or JDC staff. One mother wrote,

"With help from those from JDC, those who know [relative] the best gave the best advice on Who, What, Where & When would fit [relative's] needs. Just like a Good Caring Mother, she KNOWS what her child needs."

Some respondents did their own research on alternative SODCs and CILAs that were available to them and possessed features important to them (distance to their home or availability of services). In some cases, the respondents visited these sites.

“I visited the choices available to me. I wanted her to remain in the same day program to keep her life as much the same as possible.”

“We ruled out Chicago area facilities and places very far from home, but we tried to keep an open mind and listen.”

“We toured facilities in [list of locations]. Despite the fact that it would have been easier on us to move [relative] closer to home ... we developed our own needs assessment and determined it would be in his best interest to keep his life consistent and to allow him to live in a community we knew would accept him. We looked at [agency] and [agency] in [city]. [He] would be allowed to attend the same day program at either location. We preferred the homes we saw at [agency 1] because they offered security we initially didn't find at [the other agency]; however, [agency 1] was willing to accommodate us and meet our needs. Our family had a lasting relationship with [agency1] and many of their staff knew [relative], so we chose them.”

Services

Overview of Services at JDC

Respondents were asked whether, while living at JDC, their relative participated in: 1) developmental training (DT)/day program, 2) community employment, or 3) volunteer activities in the community. Table 6 (next page) summarizes the services that relatives participated in. The overwhelming majority (95%) participated in a DT or Day Program. Less than 2% had jobs in the community and none, guardians reported, participated in volunteer activities. Respondents indicated that two relatives did not participate in any activities during the day.

Table 6: Services at Jacksonville Developmental Center (N = 65)

	n	%
DT/Day Program	62	95.4
Community employment	1	1.5
I don't know	1	1.5
No response	1	1.5
Community volunteering	0	0.0

Respondents were asked about what types of recreational activities their family members participated in at JDC (Table 7). Additionally, they were asked if their family member had a desire to use a computer, internet, and/or a telephone and if they had access to these devices. Approximately 26% of the respondents stated that their relative had access to a telephone. One guardian reported their family member had a desire to use a computer but did not have access to one. Two guardians reported their family members had a desire to use a telephone but did not have access to one.

Table 7: Comparing Desire to Use Recreational Activities and Access to Them at JDC

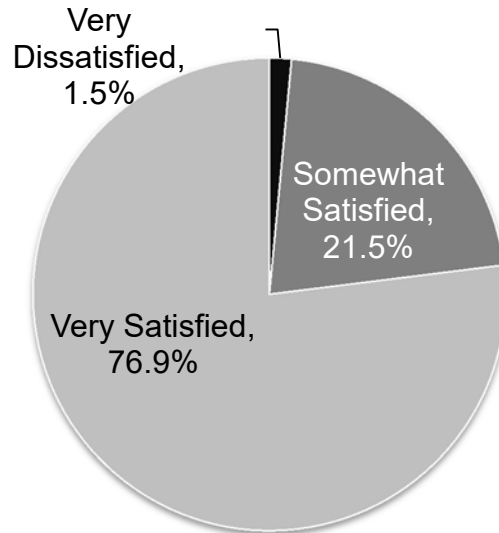
	No desire to use	Desire to use
Use a computer		
No access to	63	1
Has access	0	1
Use the internet		
No access to	65	0
Has access	0	0
Use a telephone		
No access to	46	2
Has access	9	8

Satisfaction with services at JDC

Respondents were asked to describe the level of satisfaction they had with the services their relative received at Jacksonville, using a scale of 1 (very dissatisfied) to 4 (very satisfied). The average score on this item was 3.74 (SD = .538), indicating that the average respondent was satisfied to very satisfied with the services at Jacksonville. As illustrated in Figure 1, more than 98% (98.4%) of the respondents reported being either

somewhat satisfied or very satisfied with the services offered at JDC. Only 1.5% reported being dissatisfied with services.

Figure 2: Satisfaction with services at JDC (N = 65)



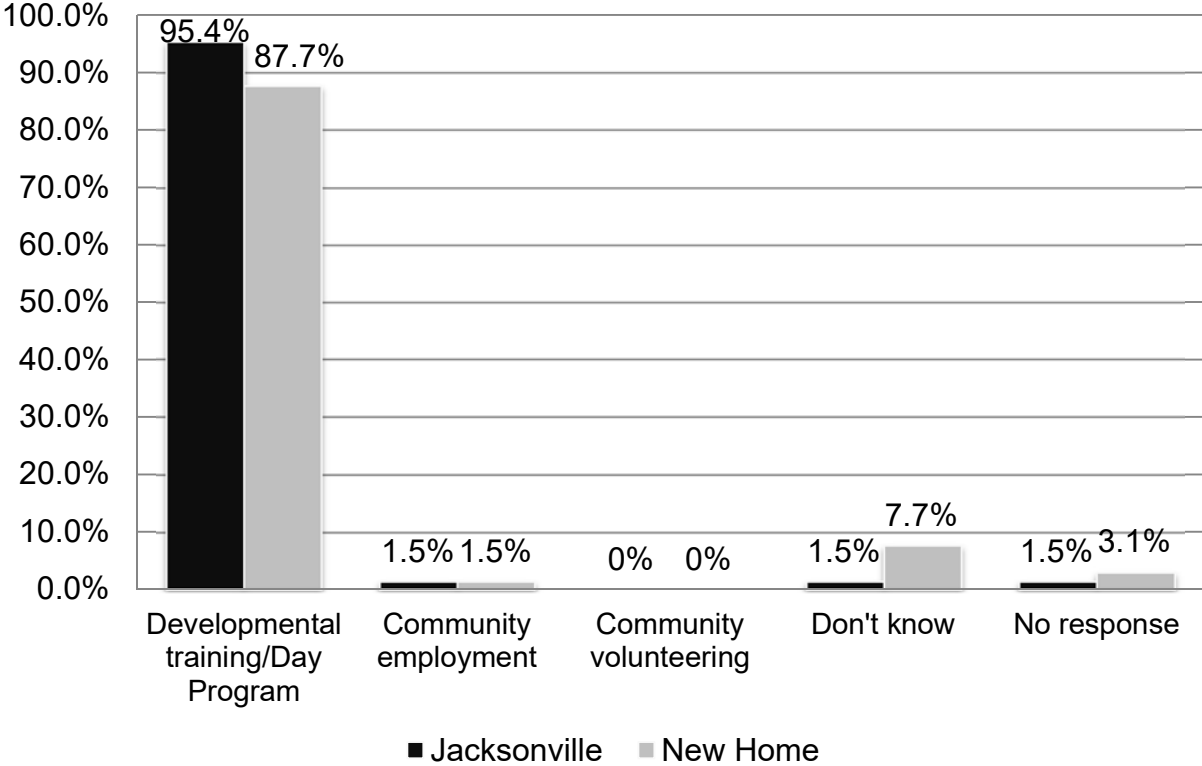
* Percentages do not add up to 100% due to rounding

When compared to younger survey respondents, older respondents (>65 years old) were significantly more likely to report being satisfied with the services that were offered at Jacksonville (89% vs. 63% respectively) ($p < 0.05$). When compared to male respondents, female respondents were more likely to report being “very satisfied” with the services offered at JDC (84% versus 62%; $p < 0.10$).

Comparing Services at JDC and Relative’s New Residence

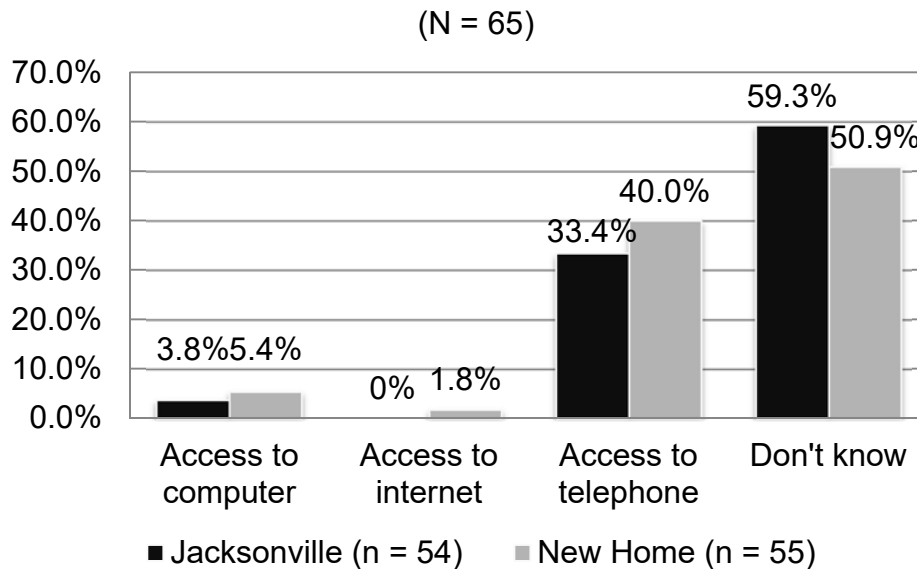
Respondents were asked about the type of programming their relative was involved in at the new residence. Six family members stated that their relative participated in a Developmental Training/Day Programming while at JDC but did not in their new home. One individual began a Developmental Training/Day Program at their new home, when they had not been involved in one at JDC. One respondent stated that their family member participated in community employment both at Jacksonville and their new home (Figure 3, next page).

Figure 3: Comparing services at JDC and at new residence (N = 65)



Respondents were also asked if their family member had a desire to use a computer, internet, and/or a telephone and if they had access to these technologies (Figure 4, next page). One respondent reported that their relative had access to a computer at JDC but not at their new home. Another respondent indicated that their relative did not have access to a computer at JDC but did at their new home. In terms of telephone access, one respondent reported that their relative had access to a telephone at JDC but not at their new home while five respondents reported that their relative did not have access to a telephone at JDC but did at their new home.

Figure 4: Comparing access to computers, internet, and telephones at JDC and new residence



Respondents were asked to provide their opinions on “How their relative is doing now.” Many respondents talked about the services their relative needed or have available to them including day programs. Responses included,

“[Relative] enjoys his new living situation and also appears to be content attending Developmental Training. Vocational staff have offered [relative] real work but he most often prefers Developmental Training.”

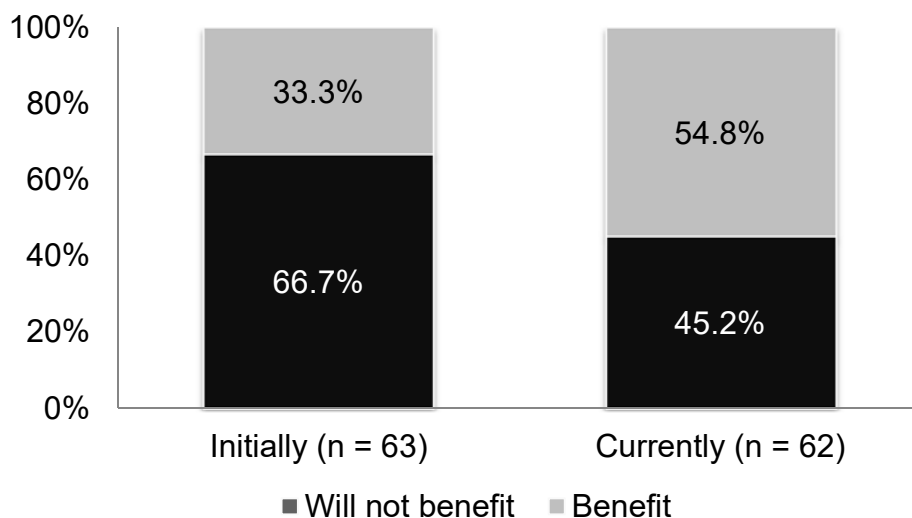
“[Relative] has just started work 2 days a week - which is the best thing for him. He wants to work (day program) 5 days a week - very important to him. Very happy at [SODC].”

PERCEIVED BENEFITS FROM A MOVE TO THE COMMUNITY

Respondents were asked to what extent they “Initially” agreed with the following statement, “My relative would benefit from a move out of an institution and into a community placement.” In addition to asking respondents about their initial level of agreement with the statement, “My relative would benefit from a move out of an institution and into a community placement” at the time the closure was first announced,

respondents were also asked for their current level of agreement with that statement approximately one year after the closure announcement. A greater percentage of respondents currently felt as though a move into the community was beneficial to their relative ($p < 0.001$) as compared to their initial feelings (Figure 5).

Figure 5: Changes in beliefs whether relative would benefit with a move into the community



Twenty-four respondents initially indicated that their relative would not benefit from a move to the community but they currently believe that their relative did benefit from a move. Those respondents included 12 parents, seven siblings, three other family members and two state guardians of people who went to: an SODC (9), a CILA (6), or an ICF/DD (4). Five respondents did not indicate to which type of setting their family member moved.

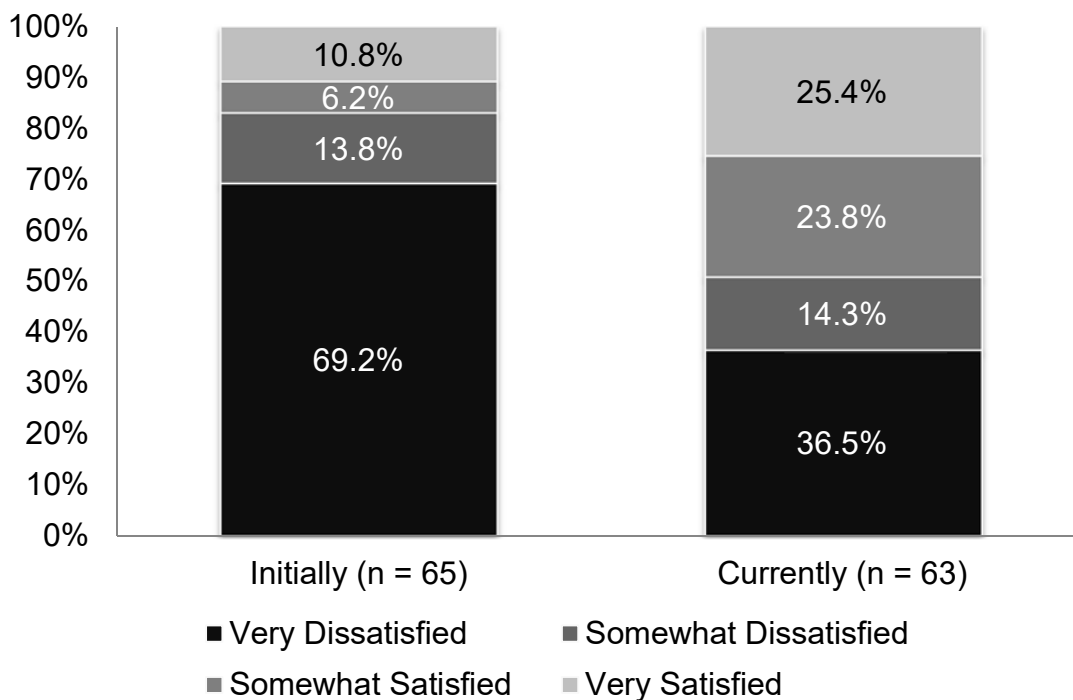
Twenty-four respondents initially indicated that their relative would not benefit from a move to the community but they currently believe that their relative did benefit from a move.

SATISFACTION WITH THE DECISION TO CLOSE JACKSONVILLE

Initial Satisfaction Level with Decision to Close JDC

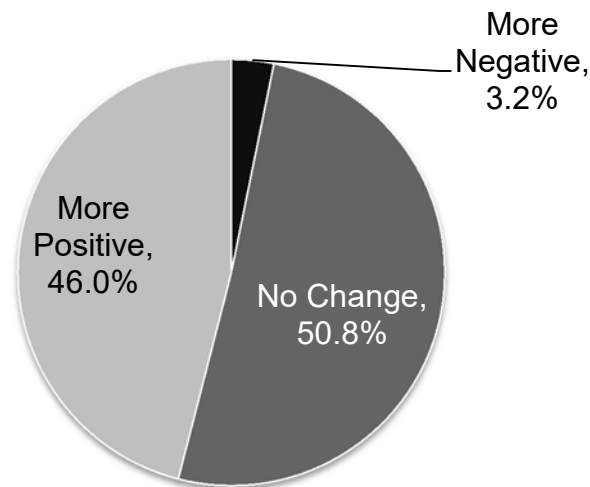
Respondents were asked about their level of satisfaction when the decision to close Jacksonville was first announced. The four options ranged from “very dissatisfied” to “very satisfied”. Eighty-three percent of the respondents indicated that they were initially “dissatisfied” or “very dissatisfied” with the decision to close JDC. Only 17% reported satisfaction with the decision. In addition to asking respondents about the level of satisfaction they felt when the decision to close Jacksonville was first announced, respondents were also asked for their level of satisfaction with the decision to close JDC approximately one year after the closure announcement. More respondents felt currently satisfied with the decision to close JDC as compared to their initial opinions (Figure 6).

Figure 6: Comparing initial and current satisfaction levels with the JDC closure decision



This allowed examination of how individual satisfaction has changed since the JDC closure announcement. In order to determine this change, a new variable was computed which subtracted respondents' initial level of satisfaction with the closure from their current level of satisfaction. A score of 0 on this item indicates that the respondent's level of satisfaction did not change. A positive score indicates a more positive feeling regarding closure over time, while a negative score indicates a more negative view of closure over time. The average score on this item was .79 (SD = 1.18), meaning that the average respondent felt slightly more positive about the decision over time. Figure 7 illustrates the change in satisfaction perception. Overall, the vast majority of respondents felt no change or more positively about the decision to close JDC. Only 3% of respondents felt increased negativity about the decision to close JDC.

Figure 7: Change in satisfaction with decision to close JDC over time (n = 63)



Impact JDC Closure Had on Guardians

When respondents were asked how the JDC closure affected them, many stated that the closure caused them to feel more anxiety and fear about the future and in terms of what would happen to their relative should their new home close or not be capable of meeting their family member's needs. One person said,

“Our peace of mind is affected because we do not know if [agency] will keep him if his health get(s) bad or his pinching aggression increases. We did not have to face this problem when he was in [the] SODC.”

Some respondents stated this was not their first experience with an SODC closure. Having gone through multiple SODC closures added more stress and burden to the families. One respondent stated, “This is the third closure that we have been through. Each change is difficult for her and I hope this is her last move.” Another said, “It was very stressful and disheartening trying to find a suitable place for him. We had gone through this with the closure of Alton's DD Unit. Once was enough.”

“This is the third closure that we have been through. Each change is difficult for her and I hope this is her last move.”

~ family member

CHOOSING A NEW HOME

First Choice of New Setting for Relative

Respondents were asked which type of setting was their first choice for their relative to transition into. Options provided were: another State Operated Developmental Center (SODC), an Intermediate Care Facility for persons with Developmental Disabilities (ICF/DD), a Community Integrated Living Arrangement (CILA) or a Skilled Nursing Facility (SNF). Table 8 (next page) summarizes the respondents' first choice of a new setting for their relative. The majority (40%) indicated that their first choice of a setting was another SODC. Nearly a third selected a CILA (32.3%), while just over 10% selected an ICF/DD (12.3%). The remaining 16% did not answer this question. Slightly more than half the respondents (55.4%) stated that their relative was placed in their first choice of setting.

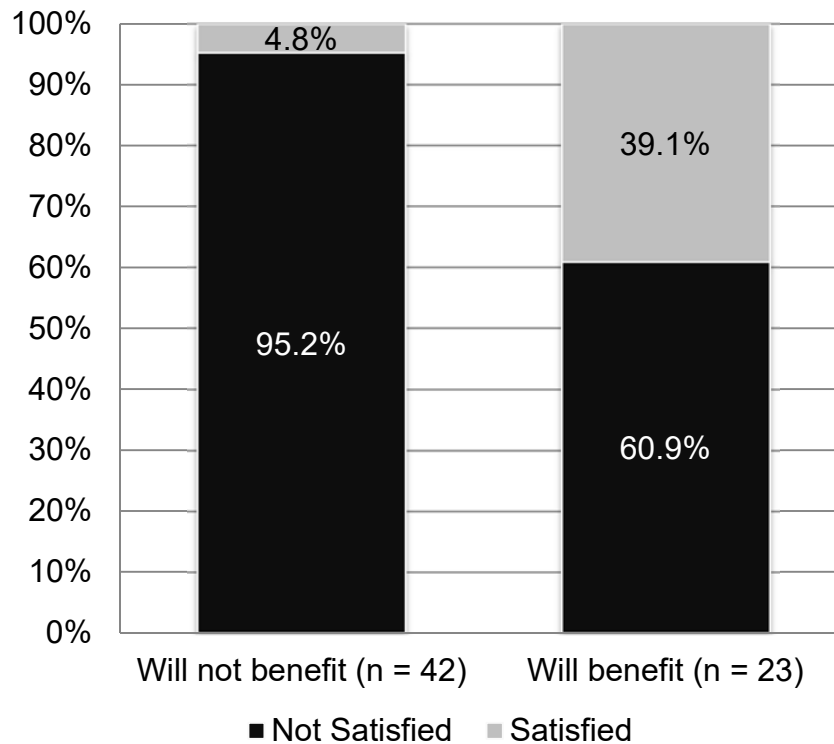
**Table 8: First choice of setting for relative
(n = 65)**

	n	%
Residential settings		
Another SODC	26	40.0
CILA	21	32.3
ICF/DD	8	12.3
Did not answer	7	10.8
Other	3	4.6
SNF	0	0.0

Of the 26 respondents whose first choice of setting was an SODC, 22 reported being “very dissatisfied”; two reported being “somewhat dissatisfied”; and two reported being either somewhat “satisfied” or “very satisfied” with the decision to close Jacksonville ($p < 0.05$).

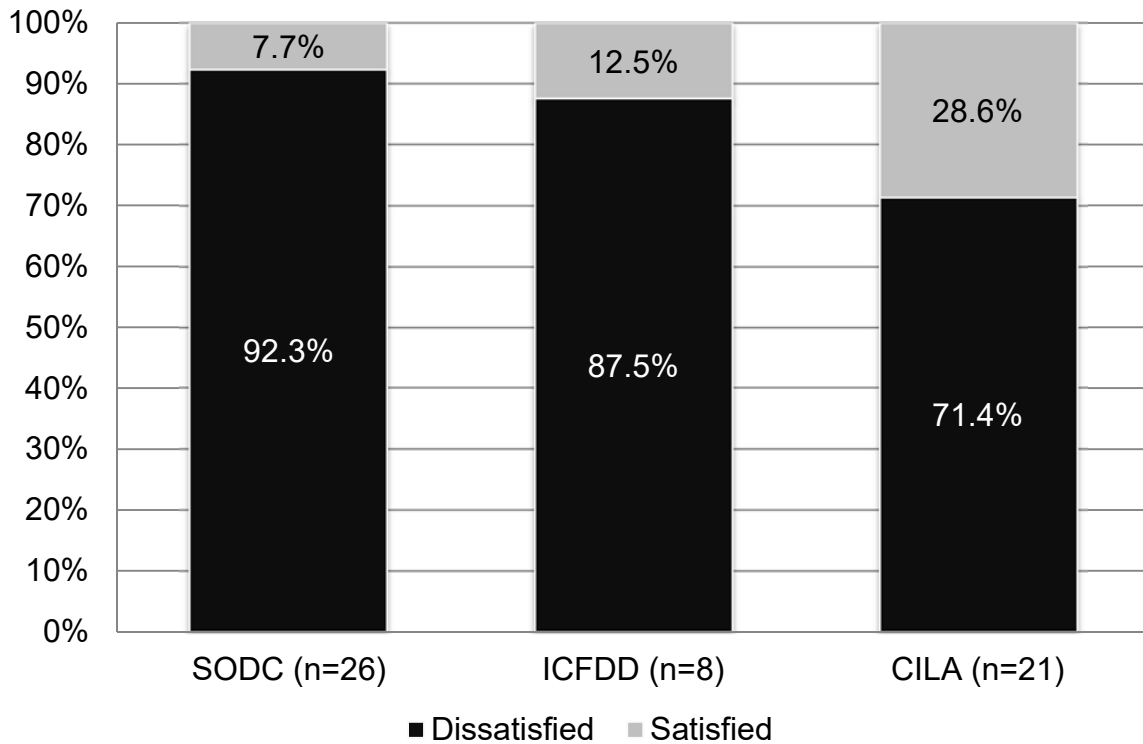
A greater percentage of respondents who felt that their relative would benefit from a move from JDC to a community setting were satisfied with the decision to close JDC (Figure 8, next page). This was significantly different ($p < 0.001$) from respondents who believed that their relative would not benefit from a move to a community setting. Fourteen respondents (six parents, six siblings, and two other family relatives) who felt that their relative would benefit from a move to the community were initially dissatisfied with the JDC closure announcement.

Figure 8: Perceived benefit from move by initial satisfaction with closure announcement (N = 65)



Regardless of preferred new setting, the majority of respondents were dissatisfied with the decision to close JDC (Figure 9, next page). Over 92% of respondents whose first choice of setting was another SODC (n=24) reported being “dissatisfied” with the decision to close Jacksonville. Over 87% who preferred an ICF/DD indicated dissatisfaction with the closure, while 71% of those preferring a CILA placement were dissatisfied with the closure announcement.

Figure 9: Choice of setting for relative by initial satisfaction with closure decision (n = 55)



Where Did They Move?

Respondents were asked what type of setting their relative actually moved to. The response options were another SODC, an ICF/DD, a CILA, or an SNF. Table 9 (next page) describes where survey respondents indicated that their relative moved. Approximately 60% of relatives of survey respondents moved to a CILA (comparable to the 62.9% of all former JDC residents who moved into a CILA); 21% indicated that their relative moved to an ICF/DD (as compared to 9.6% of all former JDC residents); and 19% in to an SODC (compared to 27.5% of all former JDC residents. Data suggests that survey respondents were over-represented by those related to people who moved into an ICF/DD and under-represented by respondents whose relative moved into another SODC.

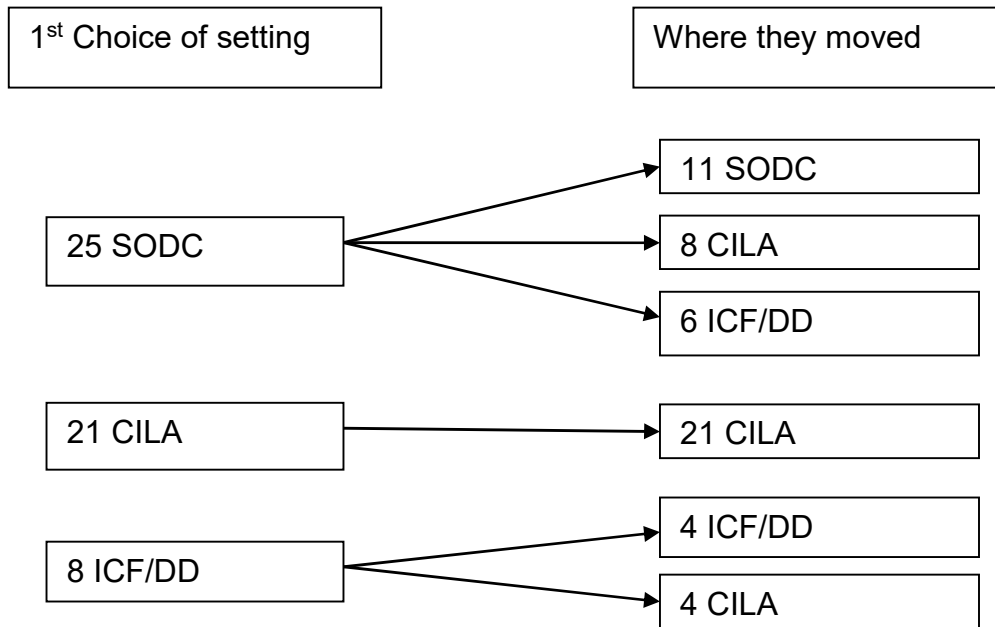
**Table 9: Mover's new residence
(n = 63)**

	n	%
CILA	38	60.3
ICF/DD	13	20.6
Another SODC	12	19.0
SNF	0	0.0

Respondents were asked if the new setting was a permanent or a temporary home (before they moved to another setting). Fifty-two respondents (80.0 %) stated that the move was permanent; four (6.2%) indicated it was a temporary move and nine (13.8%) either did not know or were not sure.

Respondents' answers for their first choice of new setting for the relative were compared to where they actually moved. Fifty-five percent of the respondents indicated that their relative went to their first choice of setting; 33.8% of the respondents indicated that their relative did not go to their first choice of setting; and 10.8% of the respondents did not answer this question. Figure 10 (next page) compares the 54 respondents who answered both questions: their first choice of new setting and where they actually moved. More than half the respondents (56.0%) whose first choice was another SODC moved either to an ICF/DD or a CILA; 50.0% whose first choice was an ICF/DD moved to a CILA; 100% whose first choice was a CILA moved to a CILA. However, the choice of new residence reported by the guardian/family member and that of the individual who moved from JDC might differ. This phase only reported the opinions of the family member or guardian.

Figure 10: Comparing respondent's first choice of new setting and where they actually moved (n=54)

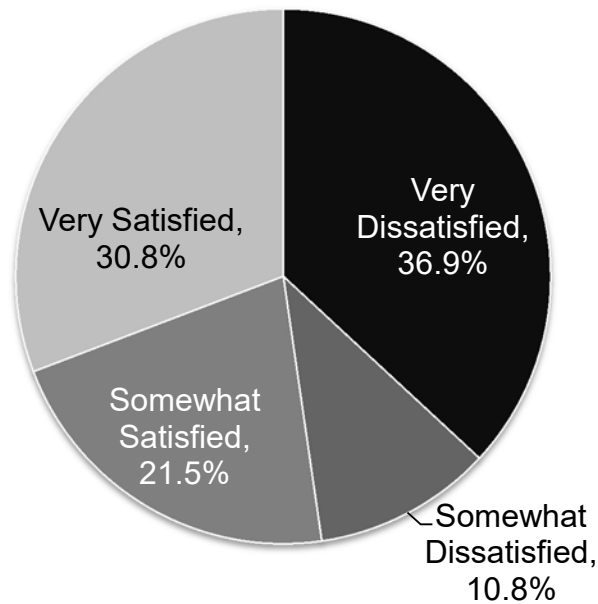


There were no significant differences in satisfaction with the closure process, belief if their family member would benefit from a move to the community, or satisfaction with current living situation by first choice of setting.

The Closure Process

Respondents were asked to describe their level of satisfaction with the *closure process*. The four responses ranged from “very dissatisfied” to “very satisfied”. The average score on this item was 2.46 (SD=1.28). Slightly over half of the respondents (52.3%) reported satisfaction with the process (Figure 11, next page).

Figure 11: Satisfaction with the closure process (N = 65)



Respondents were also asked to provide information about their transition process. Some respondents indicated they felt rushed to make a decision and that communication with the transition team was poor. One respondent indicated insufficient information was given on the placement her son went to (an ICF/DD) and one respondent was dissatisfied with the person-centered planning visual goal setting process.

“My issue was with the lack of consideration and communication around his move - there was no transition - no adjustment period”

“Transfer process was done in under cover by DHS. They did not follow the process what they said they will. No information was given on any ICF/DD.”

“I was extremely disappointed in the role CRA played in the process. They ... had one face to face meeting with me and [individual who moved from Jacksonville] and produced a cute graphic poster of his life concerns and needs -- and then never heard anything from them.”

Many respondents mentioned they received helpful assistance from the JDC staff.

“JDC helped to keep [resident] with the same roommate to the same home.”

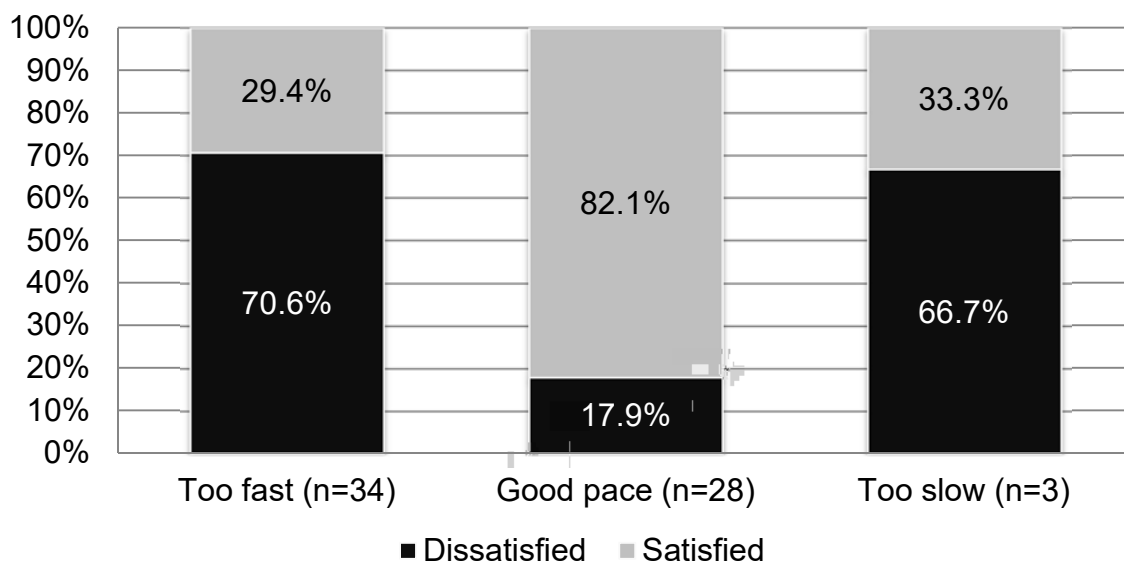
“This time the staff were looking out for the residents and made them all feel relax and that is was like going to a picnic. HATS OFF to them - Thank God.”

“The staff at JDC were very helpful, they helped guide us through the move.”

Pace of Closure

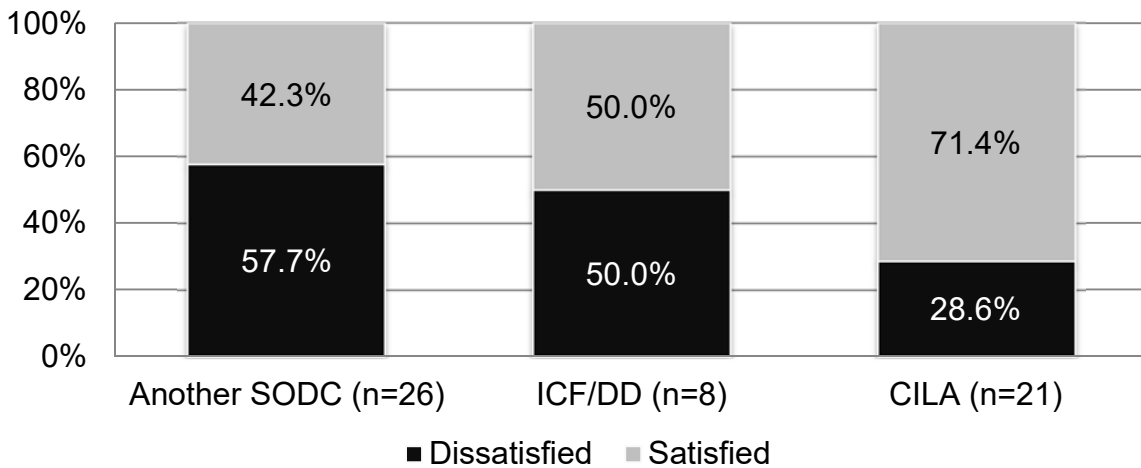
Respondents were asked how they felt about the pace of the closure process. More than half (52.3%) felt the process was too fast. Five percent felt it was too slow. Respondents who felt the closure process was too fast or too slow were more likely to be “very dissatisfied” with the closure process (Figure 12) ($p < 0.001$). All of the state guardians ($n=8$) felt the closure process proceeded at a good pace.

Figure 12: Satisfaction with closure based on perceived pace (N = 65)



While not statistically significant, a greater percentage of respondents whose first choice was a CILA were satisfied with the actual closure process (Figure 13). A greater percentage of respondents whose first choice of setting was another SODC were dissatisfied with the closure process.

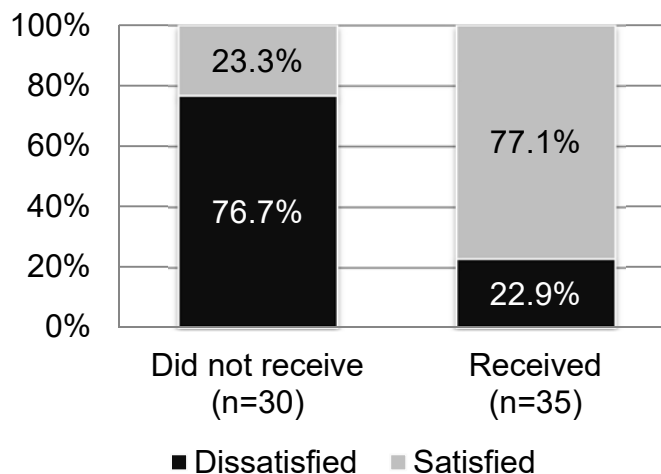
Figure 13: Closure process satisfaction by first choice of setting (n = 55)



Perceived Receipt of Adequate Information on Providers

Respondents were asked if they received adequate information on providers prior to making a choice of a new residential setting (Figure 14). Respondents who reported not having received adequate information were more likely to report being “very dissatisfied” with the closure process ($p < 0.001$).

Figure 14: Perceived receipt of adequate information by satisfaction of closure process (N = 65)

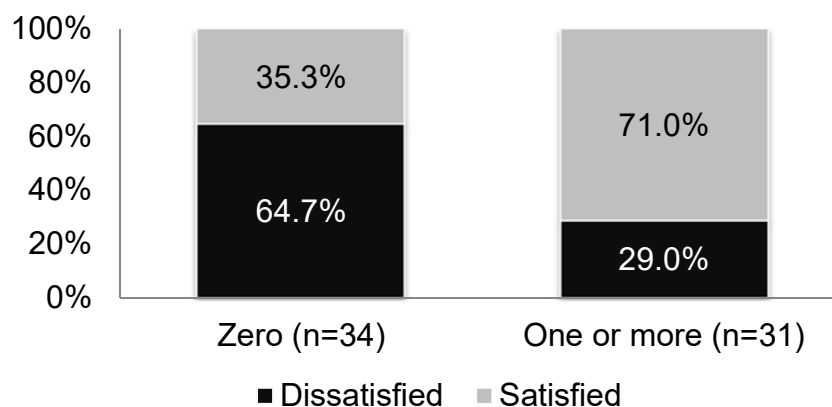


Respondents were also asked to share their feelings regarding the closure process. The following response pertains to one respondent’s perception of insufficient or poor quality communication with the transition team.

“After insisting that we wanted SODC - we were called to a meeting - told [the] SODC individual would go to. It was not suitable for us or the individual we were told to take it or leave - right now. More conversation - OK we were given a better choice. Individual moved in 2 days. Really, really poor communication and public relations. I am satisfied with where we are now but concerned about the future.”

Respondents were asked if their relative visited their potential new residence prior to moving in (Figure 12). More than half (52.3%) of the respondents stated that their relative did not visit their new residence prior to moving. Figure 15 illustrates that respondents who stated that their relative did not visit their new residence were significantly more likely to report being dissatisfied with the closure process (64.7% vs. 29.0%) ($p < 0.001$).

Figure 15: Closure satisfaction by whether relative visited new residence prior to moving (N = 65)



Respect During Closure Process

Respondents were asked to rate how much they agreed with the statement “I feel my opinions were respected during the closure process.” The four responses ranged from “strongly disagree” to “strongly agree”. The average score on this item was 2.69

(SD = 1.15). Two-thirds of respondents (66%) reported that they felt their opinions were respected (Figure 16).

Figure 16: Opinions were respected during the closure process (n = 62)

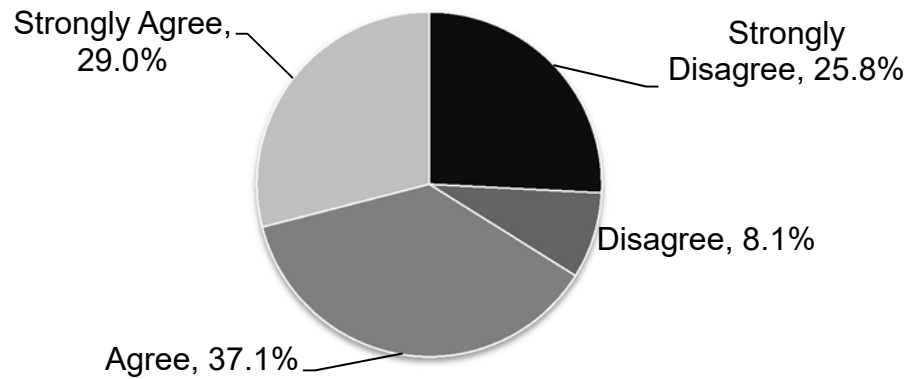
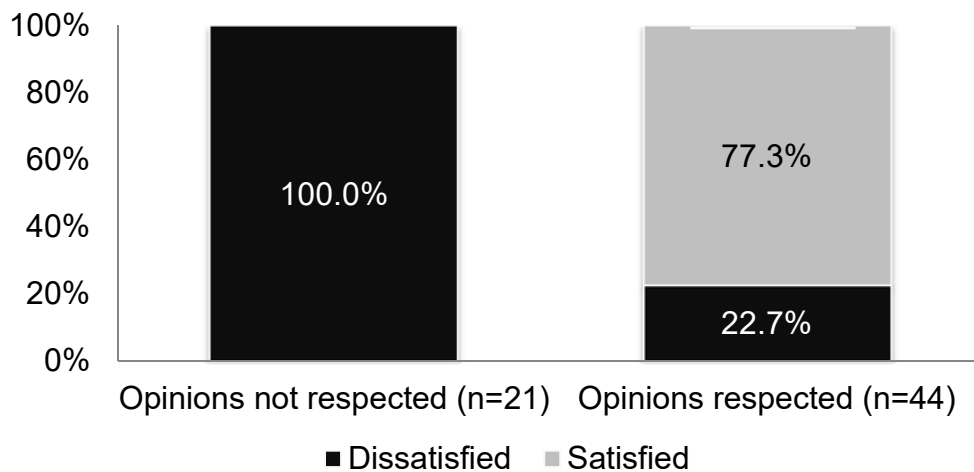


Figure 17 illustrates the relationship between closure satisfaction and whether the respondent felt respected or not. Respondents who felt that their opinions were respected were more likely to be “Satisfied” with the closure process ($p < 0.001$).

Figure 17: Closure satisfaction by if opinions were respected (N = 65)

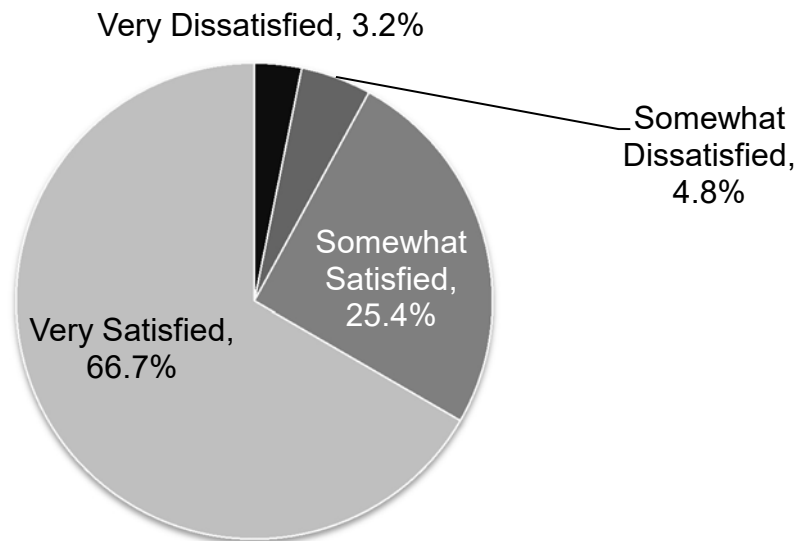


Respondents who felt that their opinions were respected were more likely to be “Satisfied” with the closure process.

Satisfaction with Relative's Current Living Situation

Respondents were asked what level of satisfaction they felt with their relative's current living situation. The four options ranged from "very dissatisfied" to "very satisfied". The average score on this item was 3.56 (SD = 0.74) indicating that the average respondent was "very satisfied" with their relative's current living situation. Of the 63 responses, a majority reported being very satisfied (66.7%) with approximately a quarter of respondents indicating being "somewhat satisfied" (25.4%) with their relative's current living situation (Figure 18). Two individuals did not answer this question.

Figure 18: Satisfaction with relative's current living situation (n = 63)



Safety of Neighborhood

Respondents were asked how safe they felt their relative's new neighborhood was. The response options ranged from 1 (not at all safe) to 4 (very safe). The mean score was 3.68 (SD = 0.51). The majority (60.0%) felt that the neighborhood was "very safe." Just under a quarter (24.6%) felt the neighborhood was "somewhat safe." One respondent (1.5%) felt the neighborhood was "not very safe." Nearly 14% did not answer this question.

Satisfaction with New Placement

Respondents were also asked how much they agreed with the following statements: 1) “My relative receives adequate supervision at their new home;” 2) “My relative likes the staff that works with them at their new placement;” and 3) “My relative gets along with their new housemates.” All these questions were scored from 1 (strongly disagree) to 4 (strongly agree).

The average response for adequate supervision was 3.64 (SD = 0.55), indicating that on average respondents agreed that supervision was adequate. The overwhelming majority of respondents (96%) believed that their relative received adequate supervision.

The majority (84.6%) either strongly agreed or somewhat agreed that their relative liked their new staff, while 15.4% did not know or weren’t sure.

Nearly eighty-two percent (81.5%) of the respondents agreed that their relative got along with their new housemates, while 3.1% of the respondents reported that their relative did not get along with their new housemates. Four respondents (6.2%) stated that their relative did not have any roommates and 9.2% of the respondents did not know if their relative got along with their housemates.

Comparing Staff at Current Residence to JDC Staff

Respondents were also asked how much they agreed with the statement: “The people who work in my relative’s present home are as knowledgeable, as skillful, and as supportive as the staff who worked at JDC.” A vast majority (84.6%) either “somewhat agreed” or “strongly agreed” with this statement.

Respondents were also asked how much they agreed with the statement “My relative likes the staff that work with him/her at the new placement.” A majority of the respondents (n=55, 84.6%) either “strongly agreed” or “somewhat agreed” with the statement that their relative liked the staff members who worked with them in their new home. Ten respondents stated that they either did not know or were not sure. None of the respondents reported that their family member did not like their staff.

Respondents were asked for their opinion on how their relative was doing now. Some indicated that the transition had been difficult. Other people have adjusted well,

as one sibling explained, “My brother has adjusted well to his new home - the staff is friendly and he seems to like it there.”

Commute Time and Frequency

Respondents were asked, “How long did it typically take you to travel from your home to JDC?” The response options ranged in 30 minute increments from “less than 30 minutes” to “more than 3.5 hours.” The majority of respondents indicated a commute time of less than two hours (60.0%), while more than a quarter (27.7%) reported a commute time less than one hour. Respondents were also asked how frequently they visited their relative in the past year from “not at all” to “weekly or more.” The majority of respondents visited their relative at least 3-4 times per year (36.9%); more than a quarter (27.7%) reported visiting monthly; and 27.6% at least once a year or less.

Respondents were asked how long it typically takes them to travel from their home to their relative’s new home. Response options ranged in 30 minute increments from “less than 30 minutes” to “more than 3.5 hours.” The majority of respondents indicated the commute time was less than two hours (56.9%). Respondents were also asked how frequently they visited their relative in the past year from “not at all” to “weekly or more.” The responses for this question were recoded into “not at all,” “once a year,” “3-4 times per year,” or “more than 4 times per year.” The majority of the respondents visited their relative at least 3-4 times per year (69.2%).

When compared to commute time to and frequency of visits to JDC, nine respondents indicated that they visited their relatives more frequently at their new home while eight respondents had a decrease in visitation frequency. Seventeen respondents had shorter commute times as compared to their commute to JDC, while 14 respondents had longer commute times.

Respondents were asked to describe the effects that the JDC closure had on their family; some stated that visiting their relative was positively or negatively impacted by the new location. Respondents stated that living near Chicago and the amount of

time it took to drive to their relative's new home would negatively impact their ability to visit their relative.

"We worried about the transition. We were very disappointed that our brother moved to the Chicago area. ... We are pleased with the home and staff but not the location."

"It was scary to our son thinking he might not have a place to live. It was also disappointing that there were few choices of local CILAs as we were told in the beginning. Our goal is to have him closer than 3 hours away."

"It was scary to our son thinking he might not have a place to live. It was also disappointing that there were few choices of local CILAs as we were told in the beginning. Our goal is to have him closer than 3 hours away." ~ parent

When the family member moved closer, respondents stated that their relative called them more often and they (the respondents) were able to visit their relative more frequently.

"We are now able to talk to and visit [relative] more easily. Over the 4th of July period his sister and brother visited him for the first time in three years."

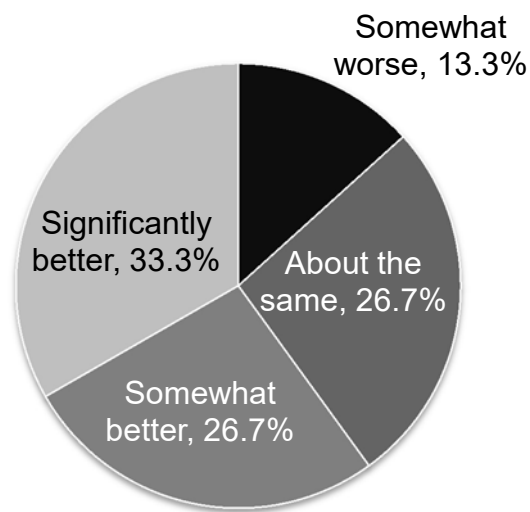
"It [the closure] has enabled our relative to live closer to his hometown where his family lives."

"We are now able to talk to and visit [relative] more easily. Over the 4th of July period his sister and brother visited him for the first time in three years." ~ family member

Compared to When They Lived at JDC, Is Relative Better or Worse Off?

Respondents were asked if they felt their relative was better or worse off as compared to when they lived at JDC (Figure 19). The five response options ranged from “significantly worse” to “significantly better”. The average score on this item was 3.80 (SD = 1.05) indicating that the average respondent felt that their relative was “better off” as compared to when their relative lived at Jacksonville. One respondent was not sure/didn’t know. Four respondents did not respond to this question. Of the 60 responses, a majority (60.0%) reported that their relative was better off when compared to when their relative lived at JDC. Twenty seven percent felt their relative was about the same. Eight respondents felt their relative was somewhat worse off when compared to when they lived at JDC. Of the eight who felt their family member was worse off, half (n = 8) favored another SODC as a new residence for their relative, one preferred an ICF/DD, two preferred a CILA, and one did not respond to the question about the preferred new residence for their family member.

Figure 19: Compared to when your relative lived at JDC, do you think s/he is better/worse off? (n = 60)



Respondents were asked to describe any changes they have observed in their relative since their transition from JDC. Respondents who felt that their family member was better off saw improved behavioral outcomes, increased privacy, and improved access to community resources as indicated by the following quotes:

“[Relative is] able to access community more. Less behavioral issues.”

“In the 2nd CILA, he has had decreased outburst[s], less anxiety, interacts well with staff. He still needs prompts with hygiene. He goes to a day program to work and interact with others.”

“[Relative] has more privacy by having his own room. He has more access to the community.”

“He is content where he is, looks a little healthier because the meals offer more variety, and he is allowed to tap on his make-shift drums (cookie tins) for longer durations, which always makes him happy. The home doesn't have the echoes the large day room had at JDC, and [relative] is upset by loud noises, so this is better.”

“He has improved significantly in speech, cognitive and happiness due to the support of staff at [CILA home]. Their constant interaction with all 4 clients is super.”

“Even though we were very upset about Jacksonville closure, for us, it has proven beneficial. He is in a more controlled situation and doing MUCH better.”

Some respondents felt their relative was worse off, typically due to the presence of new behaviors. One person stated,

“I tried to keep the transition to as minimal changes as possible, however, she developed behavior problems at day program that they have never seen. She became violent, angry, aggressive, SIB, screaming - all for no reason - no provocation. Has lessened some to date.”

Another said, “Behavior problems, elopement, since moving on the increase. The relative seems to know how to extend the behaviors without stopping. It seems they [the staff] can get the relative under control quickly.”

PHASE II: STAKEHOLDER INTERVIEWS

METHODS

Between February and July of 2013, 38 interviews/focus groups were conducted with 53 participants across the State. Over 28 hours of interviews were conducted, ranging from just over 16 minutes to nearly three hours in length. For the purpose of this phase of the evaluation, a stakeholder was defined as anyone who was involved in the closure in a professional capacity. Potential interviewees were identified by the research team with the assistance of Division of Developmental Disabilities (DDD) staff. Additional potential participants were identified through the “snowball” technique in which interviewees were asked to recommend individuals who should be included in the evaluation. Potential interviewees were contacted either by email or telephone by the lead researcher, and if they indicated a willingness to be interviewed, a date/time was set at the location of their choosing.

The vast majority (95%, n = 36) of the interviews were done in person, though two individuals (5%) opted to conduct the interview over the phone. All interviews were digitally recorded and transcribed and then reviewed for accuracy and coded by six members of the research team. After coding was completed, key themes were drafted and negotiated by the full team until consensus was reached. Use of methods such as these strengthens qualitative research thus improving the validity and consistency of the conclusions (Patton, 2002).

An interview guide was used (see Appendix B) allowing for more of a conversational tone during interviews. Interview participants were asked questions along four major areas of inquiry: closure process, communication, resident transition and quality assurance.

FINDINGS

Guiding Principles/Values

Three overarching themes emerged from the stakeholder interviews: support for smaller community settings, a desire for family-centered approaches, and a commitment to person-centered practices.

Smaller Community Settings

The Division of Developmental Disabilities employed an Active Community Care Transition (ACCT) process throughout the closure. A core focus of the ACCT process was to transition individuals out of JDC and into smaller community-based settings with a maximum of four people residing in a home through the use of individualized plans of support. Respondents were overwhelmingly supportive of this model and saw it as “normalizing”. One interviewee commented,

“...if you are living with more than one adult in your household, it's either your adult children or your parents. It's the family members, not an unrelated adult unless you choose a roommate which is possible but most people only choose one, two, maybe three at most...Houses are two, three bedroom homes. So if everybody has their own bedroom, then three people. There are no eight bedroom homes out there. There are mansions, but that is not where we are placing people.”

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~ stakeholder

Family-Centered Process

Stakeholders expressed the desire to make sure that the voices of families were being heard with regard to the needs of their relative, such as where they should live and what types of supports they required. One person commented, "...we said to...guardian[s], if what we build into the plan, you feel it is not sufficient enough, tell us what you want and we will work it into the plan. So some family [members] could say, 'My guy needs more than that.' And we were willing to put that into the plan. It's again individual." Another stated, "If it is the guardian's choice, they should have all the options at the table. They would get to choose what might be the best transfer because you don't want to move somebody three times when they are already easily confused."

Additionally, stakeholders expressed that they understood guardians' knowledge of their relative was often better than government officials and as such, they should have an active voice during transition meetings. To that effect, one person said,

"Give the families informed choice and there are large places, small places, places close to them, further away, the guardian should be the one making the choices rather than the government. And you have allowed people to stay in state ops for years and years and cost \$300 a day."

Person-Centered Planning

The transition process supported the rights of individuals with IDD to live in a place of their choice, and not have this decision be determined by the supports the individuals might need in the future. In order to help achieve this goal a set of ACCT Principles and Values² were developed so that everyone understood the main objectives in finding new homes for persons transitioning out of JDC. As one stakeholder explained,

"So one of the things we said is we need to establish a core set of values and principles. And so we established eight of them that are on the web

² ACCT Principles and Values: <http://www.dhs.state.il.us/page.aspx?item=67482>

site. We posted them and dealt with things like separating housing from supports because we said where you live is different than how you are supported. And if I don't like my provider, I should be able to change my provider, not change where I live and vice versa. So that was one of our basic principles. It was about supporting individuals and individual needs, not beds and slots. So we made that one of our guiding principles. We said that everybody should have an individual plan with an individual budget that supports their needs and their budgets should be fluid enough to move up and down as my needs change, not that I have to move every time my needs changed.”

Another interviewee indicated that person-centered planning was at the forefront of the transition process,

“And it starts with designing the supports around the person based on what works for the person or doesn't work. So it starts with the person-centered plan. The more I can gather in that person-centered planning process. I know if I did this to you it doesn't work for you then I won't do that to you and most of it is environmental. If I can control the environment, I got half the problem gone, right? If I don't do well with people touching my stuff, then don't put me in a room with lots of people that are going to touch my stuff. Part of it is just design...that's the difference between placement and what we are doing. We are designing the home and the lifestyle around the person's needs which include their mental health needs.”

The individual, along with the environment, was taken into consideration when working with providers to find an appropriate home. As one person noted,

“...you have to go to a home that is less than four persons. We also knew that people that live in centers, live in units where there are eight other persons in the living space with them - no privacy. And I don't care who you are, whether your IQ is 140 or whether it's 60, everybody needs a

place to decompress. Everybody needs to have a place where they can put their stuff and no one messes with it. Everybody needs a place for privacy for lots of reasons. So to us it just made sense that every person coming out would have their own room. And so we said you know there is nothing magic about four other than that drives the [Money Follows the Person] dollars in the system, but what it is about is figuring out what you need.”

Stakeholders wanted to assure that they were able to not only meet the needs of the person transitioning out of JDC, but to ensure that their interests and hobbies were also addressed in their new home. Stakeholders indicated that a conscious effort was made to ensure that consumers were not just placed in locations without thoughtful planning. As one respondent said,

“I want to develop a home in a neighborhood that you want or your family wants with the things that you need and want. So if you love sitting outdoors, I want to make sure there is a place for you to sit outdoors. If you like to garden, I want to make sure there is a place that you can garden. If you have trouble walking great distances, I want to make sure that I am going to get you close to services. If you use a [wheel]chair, I need to make sure that the house you have has widened doorways and ramps and roll-in showers. I figure out what you need and I build supports around you in that home. I don't try to find a home to fit you in. I go out and acquire a home based on what you need. That is very different than filling beds and slots.”

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~ stakeholder

THE CLOSURE PROCESS

Timeline

When Governor Quinn announced the closure of JDC on January 19, 2012, a target date of October of 2012 was set to transition out all 181 residents³. The last resident moved out on November 27th, 2012.

The timeline of the closure was described by many interview participants as variations of “too short/rushed.” One said, “I wish it would have taken a lot more time. [The Director of DDD] always said from the beginning, ‘It should take a year, year and one-half, if not two years.’ Getting it done in eight, nine months is really, really pushing it.” Another participant stated, “It was very, very ambitious ...” Another person echoed that sentiment saying, “I know that people have quotas and when you are trying to close...But when it becomes apparent that you're not going to be able to move people out that quickly, then you look at extending the time...”

Some providers indicated some more specific reasons why the timeline was too short. One provider mentioned that they felt rushed to get the houses ready and spent lots of time outside of normal work hours to accomplish those tasks, stating,

“...you have builders that are spending the night in sleeping bags to help you get things done just because they want to help you out and they are not getting any extra money or any extra anything. We were baking goods to take in. Literally they were giving it all they had, weekends, everything.”

Another person explained,

“We had one individual who was going to move into one of our other sites and we were like wait a minute. You know in a month this individual is going to be able to have ceiling lifts, rain tub, all these things that he needed. How can we as a provider move them into a setting that we don't have that when if you just wait another month he can have the best of the

³ One individual died prior to transitioning out of JDC.

best because that's how we're building that home because we know that one is needed for medical purposes and for lifts and for things like that? And the team agreed and that was the process that went.”

Additional stakeholders mentioned that they were also experiencing pressure to complete transitions quickly due to the closure timeline. One stakeholder stressed, “I thought it was very rushed... I felt a lot of pressure to accept clients into our program and be ready for them.”

While many thought the process rushed, some felt the time frame was adequate stating, “I think the time frame was fine. I think more of the issue was placement preparation.” However, another provider commented, “We had the locations. At the time we had three vacant properties that we were sitting on. We were ready to roll.” Another mentioned that while the timeline was adequate, there was an issue with arranging transportation to new homes which were sometimes a long distance away.

The timeline became more of an issue as some guardians refused to participate early in the process. One person explains,

“I think there were guardians who were pretty steadfast in their refusal to participate in the process until it got towards the end and it appeared that actually the lights were going to be turned off. And so then there was that kind of ‘hurry up and get it done.’”

In some cases families’ refusal to accept JDC closure, and later involvement in the transition process resulted in families having to settle for a placement that was not their first choice for their relative, often resulting in additional moves. One stakeholder said, “They were fighting for something they believed in. But some of them ran out of time and as a result are now in SODCs and now are having to go through a second transition.” It was reported that several individuals at JDC ended up being sent to other SODCs in order to close the JDC campus by the end of the year. Additional time may have allowed people to transition to their intended home without transitioning to another SODC while their home was being completed. As one person said,

“There were already individuals that were targeted for certain providers and I think they should have been allowed to at least stay where they were. Why should they have to transfer to another SODC and then a couple months then they are going to have to transition then into another home?”

Another stakeholder said,

“I think it was adequate. I think they moved fairly quickly. I mean you could tell that there was a definite push to get things done and get things closed.”

Another contributing factor to the resistance shown by guardians was that they were not completely convinced that JDC would actually close and did not want to risk moving their relative until it was absolutely clear that the institution was going to close. It was stated,

“... a lot of people understand that facilities are closing, but they would prefer to wait and take their chances then to transition their loved one to a community setting where also because of the financial climate may close. And then they are like, ‘what do I do now? And if they go will they ever be able to come back?’”

Although there were many criticisms, one person explained the need for a deadline,

“I will tell you that had a date not been picked, we would be sitting here two years from now because of the way things work. It focuses the effort and the mind”

One interviewee succinctly summed it up saying, “half of the people think we're going too fast and half the people think we are going too slow.” Another individual indicated that while speed appeared to be driving the process, the DDD Director’s rule of “It’s got

to be safe, it's got to be well planned and it's got to be appropriate," played out in almost every circumstance.

Pre-Transition Visits

Much discussion revolved around pre-transition visits and the impact of the timelines.

"Usually we try to do a daytime visit and then we do overnight visits."

Some interviewees indicated that it was difficult to adhere to the typical pre-placement visit protocol and cited the closure timeline as a reason. A provider described, "We were used to having the luxury of people being able to do pre-placement visits, get to know the staff before they move, get to see their home before they move and in the beginning we were able to do some of that. As things progressed, we did less and less of it because of the time factor."

If given more time, the adjustment process to a new environment would have gone more smoothly says a provider,

"if we had more time, I think the transition process would go a lot better if they were actually able to visit first, which I know is not always possible with agencies closing. You have to look at it if it was you or me going into a new environment and home, new people, new friends"

One stakeholder believed "the [new home] staff would have felt more prepared if they would have gotten more hands-on transition when [clients] came to us" during the pre-visits. This same stakeholder felt that during these visits the new group home staff "were just kind of back watching" while the "JDC people were over them."

Another person explained that it wasn't always the timeline that was to blame for the lack of pre-transition visits; the back and forth was confusing for some residents. One person said, "I don't want to say it was just because of distance because ... some people...They would go and come back and they would be very upset because they thought that was where they were going to go. They thought they were moving."

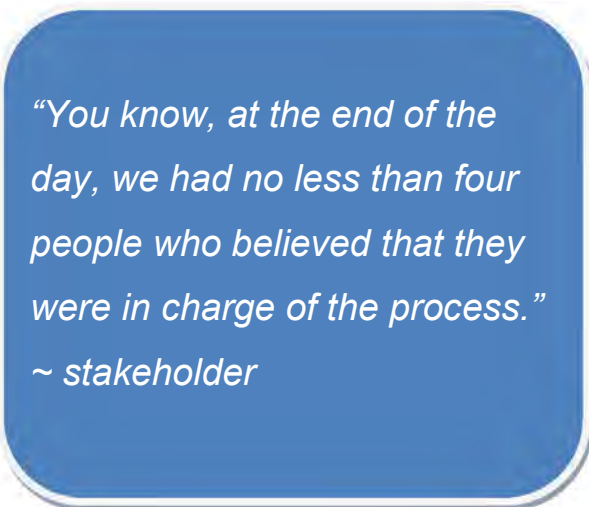
Another provider explained that it was difficult to do pre-transition visits due to the logistics of opening a new home,

“...normally when we have someone come and visit, they were able to do the overnight. You know, they are able to do those types of things and we really didn't have that availability because really it was we were opening the building, getting licensed and then moving. So some of that transition that we normally have was not there.”

COMMUNICATION

Key Point of Contact

Numerous stakeholders indicated that there was confusion over who was in charge or who was the key point of contact during the closure process. The Governor's Office seemed to be “running the show,” reported one stakeholder, who followed up saying that CRA seemed to be the “voice of the closure.” A couple of stakeholders indicated the DDD Division Director and the Transition of Care Project Manager in the Governor's office were the authorities who were delegating day-to-day tasks. Another perceived the Deputy Director of the Bureau of Clinical Services within the Division of Developmental Disabilities to be the person in charge. For some providers, JDC staff were the primary point of contact (e.g., the Qualified Intellectual Disability Professional), while others said that they viewed CRA as in charge. One individual summarized the situation saying, “You know at the end of the day, we had no less than four people who believed that they were in charge of the process.”



“You know, at the end of the day, we had no less than four people who believed that they were in charge of the process.”
~ stakeholder

Not only did stakeholders express confusion about who was in charge, but there seemed to be uncertainty about the roles of each participating entity. There was consensus among stakeholders that each entity involved in the process had difficulties

in understanding which party was doing what and who was responsible for certain tasks.

A few stakeholders stated that they had not experienced any problems with communication within the closure process. Additionally, some noted that if there were communication issues, it was limited to certain individuals and should not reflect poorly on the whole closure process. Another stakeholder explained, "Overall I thought the communication was quite good." In fact, a great number of stakeholders praised the leadership of the DDD Director. One said, "...I think that the Director just went over and above in his willingness to meet with people. I mean over and above, over the top. And it didn't matter what it meant. If somebody wanted to meet with him, he did it." Another said, "He ...is meeting with them and really trying to help families understand the process and why the end result will be very beneficial to their loved one." One stakeholder observed, "...he just veered the course, kept his sense of humor, had a long-range perspective and I think because of his leadership, everybody else kind of did that." Another said, "I found his leadership was very powerful."

Communication with JDC Personnel

Communication with JDC staff was integral in the closure process. One person noted the value of having JDC staff at the transition meetings,

"I felt though that JDC staff in our transition meetings gave a lot of good information when they would come and I really relied on them most of all because as we were going through this process and as they're explaining dietary things, behavioral things, just different aspects of that individual, the staff can jump in and say, 'And by the way, this is a quirk that person has or you know they say this is what you know he likes, but he really doesn't like this kind of food type of thing.'"

However some stakeholders felt that communication among JDC staff seemed to suffer as a result of inconsistent leadership and staff attrition. The JDC staff who knew residents the best were leaving; so they were no longer available to communicate important information to CRA or the providers. This became more problematic later in

the process when staff members with this critical information were no longer at JDC. One person described the impact of attrition,

“I think they had a lot of the State workers had left to go to other jobs and so they weren't familiar with these individuals. The nurses that were coming to the meetings a lot of times weren't familiar with the individuals and they were just reading from a piece of paper and you would ask them a question and ‘I don't know. I'll have to go back in the chart and look for that.’”

Another issue identified was a failure to keep JDC staff informed about the closure and activities. One person felt that JDC staff members were on a “need to know” basis. Another individual stated, “The communication was inconsistent...I don't think there was enough communication with the day-to-day workers of the facility. There should have been better daily communication due to the sensitivity of that closure.” Another stakeholder relayed the lack of communication with JDC staff, “...JDC staff would approach CRA to ask what was going on. There were some instances of on moving day, JDC staff didn't know that the residents were moving out and were not ready when the van showed up to move them.” One stakeholder explained that if there was better information and communication with JDC, the facility administration would have improved their credibility and significantly reduced the number of staff members who were disgruntled.

In defense of JDC staff, a couple of stakeholders indicated that they did not believe that JDC staff had the necessary supports to perform their jobs. One said, “...it almost seemed like as if JDC didn't have the resources they needed to properly follow through.” Another commented, “... that [it] certainly doesn't help them making proper transition for individuals if they are not having the resources [they] need to do that.” Further complications arose as a result of inconsistent leadership. One stakeholder reported that there had been three Center Directors at JDC over the course of twelve months, “The challenge we had there is there wasn't a consistent Center Director. The Center Director left shortly after it was announced and then we had interim Center

Directors and then we had Division people and supporting interim folks. So there was really a lack of a consistent leader there.”

Sources of Conflict/Confusion

There appeared to be a sense of conflict between the staff and residents of JDC and the administrators. One person stated,

“I think what happens in these circumstances, it becomes an 'us against them.' You have the 'us' of the administration, the evildoers in shutting down the building and the 'them' is with staff and they are going to fight against it. So they get locked into those places and it impacts how they are able to communicate with one another.”

Stress

The closure had an emotional impact on both staff and residents. One person explained,

“Well it's part of the ownership of the facility and [staff] believe they are [residents'] family members and 'we know how to take care of them better than you. We have been with them a long time...' Part of that is true. They have been with them for years.”

“...the staff believes that no one else can take care of those people but them. And every facility that I have been into that has closed has always said the same thing. 'We are the best facility.' Whether they are or not. And 'We are the only ones that take care of this type of population.' Which is also not true.”

One person observed, “Well it was very stressful for them [residents] to lose their long-time staff in particular. They had to witness the staff meltdowns.” Another stakeholder described witnessing such an event,

“I remember talking with one of the residents... And in the background there was this screaming going on. I said, 'What in the world is that?' She

said somebody is yelling at the supervisor because she didn't want to have to work another shift. And she was like very matter of fact about it, but that kind of stuff went on a lot. So I think it was very stressful for them...”

One staff indicated that “it was just overwhelming to try to keep up with our normal work and do the transitioning at the same time.”

One stakeholder shared steps which were taken to support JDC employees, including employee assistance (e.g., resume building), an employee support book and a relaxation room. Committees were formed to coordinate these activities and events.

“We [JDC Administration] had [a few] people that were depressed because of the closure announcement, or people that thought they were going to lose their jobs. So we brought in training for them, taught them how to do resumes and showed them how to do stuff. That kind of thing. We set up a book, an employee appreciation book, but it was an employee support book was what it really was. It told them everything they had to do and where to go to get it. We set up relaxation rooms on the two units that they originally had four units. We kind of transitioned that back down to two for staffing issues. Technicians-- we maintained our technicians and most of the support service workers, but nursing became an issue and we started to contract nursing.”

JDC Families

Reaction to Closure Announcement

When parents first found out about the closure there was a sense of disbelief that JDC would actually close. One person stated, “I think there was always something in the back of the minds of the people at JDC like, ‘Wow, that this isn't going to happen. They are going to talk about it, but it's not going to happen. We're going to be fine. We're not going anywhere.’”

Once family members came to realize that the State was indeed going to close JDC, however, there was a grieving process that needed to be respected before family members could proceed with transition plans. One stakeholder stated,

“People go through the grieving process, and they have to go through it. They really do, and that's where I found when somebody started to talk in that initial conversation, I would learn where they were in that process. And I can't tell you how many times in the meetings after we had the monthly meetings, I would say ‘the process is the process and we have to let them get through the process’. And really people almost can't make a decision until they get through it because first they don't believe it. Then they are very angry and that's really where the kick back is initially. And then when they realize they can be as angry as they want. But this is what is going to happen.”

Despite initial resistance to the JDC closure, when families saw the community homes into which their relative would be moving, they expressed surprise at how nice the homes were and felt more at ease with the transition out of an institution and into the community. One person said, “[Guardians] were really surprised [at] how nice it was... They said that [their relative] would really enjoy it. The one thing that they liked is that he had a lot of room to move around....” Another stakeholder commented, “...a couple of the older parents that have lost contact for years and years and years and we are like, ‘Oh my God, I never thought that he would live in a house, in a neighborhood.’”

Family Involvement in Closure Process

In general, family involvement in the closure process was limited. Several factors contributed to this including skepticism based on previous failed placements and fear. One person explained,

“Certainly the mother and father of the one individual were supportive of JDC. Did not want to see it close. Certainly had reservations because of failed placement before and various reasons for that. I mean he did have

some behaviors...So certainly as parents, you would have reservations and they wanted certain things. They knew what they were looking for if it was available.”

Families had reservations about community living in general and fears about what would happen once their family member moved out of JDC and into the community. Stakeholders indicated that there was a lack of effort to educate families on the benefits of community living and to help them understand this overwhelming process.

“The family is in terror about ‘what is going to happen to my loved one?’...And I think that there needs to be ongoing focus groups, discussions, inviting them to visit homes in the community...But I don't think that there was an opportunity that was offered to these families on an ongoing basis to just come and sit and talk. Which puts fear in the guardians... It's like ‘Oh my gosh I have to place him here or who knows where they are going to be.’ ...

“By the time they finally found us and when this first mom found us, she was so thrilled and she told everybody she could tell. We had phone calls like crazy from parents because of this mother. And I heard the same thing over and over that they really weren't getting any guidance. My experience with JDC was good, but this is what I am hearing from the parents that theirs was not so good.”

When family members were involved and active in the closure process, CRA could focus on the transition of the individual and their needs, rather than trying to persuade family members to support closure. Some family members, however, were limited in their ability to be involved with the closure process due to their age, their inability to attend nighttime meetings, and/or their inability to go and visit various community homes. One person said,

“If the family was very sure of themselves and got in there and really took advantage of everything and really tried to be involved, I think that helped more than everybody else having to reach out to the guardian instead of pulling them in...It’s always going to be better if people try to participate. And some of the guardians were always hard to reach and I don’t think it was very effective when they were hard to reach. And if they didn’t want to be involved in the [ACCT] process, that made it even harder because then there was just almost like a struggle between the whole process.”

Communication with Families

Families felt confused, overwhelmed and angry with the news of the closure of JDC. They were afraid for the well-being of their relative and wanted to be able to speak with someone who was willing to listen to their concerns and provide useful information and clarity about the transition process. One stakeholder described a guardian’s desire for support, “What she wanted was ... to be able to have somebody explain to her honestly what was happening to allow her to do everything from grieve, to be angry, to just listen and then to have action.” Another stated, “...a lot of times it was simply just somebody to listen to them. They really felt that they needed an independent person who knew the system and would listen to them without judgment and help them get what they felt they needed.” An interviewee commented, “Guardians found the process very confusing and typically sought out guidance with understanding how to understand and complete paper work.

Communication issues caused stress and anxiety for parents of individuals living at JDC. Elderly parents especially were frightened for their child. Stakeholders relayed that the parents did not feel as though they received reassurance or information about community living to help them understand how their child would be able to live in a community setting. Fears were escalated by the fact that family members were receiving phone calls from various parties and given misinformation or inconsistent information about the process, which left family members feeling confused and uneasy about the well-being of their relative. The misinformation and lack of open communication with family members, stakeholders felt, resulted in hesitation to

participate until the latter stages of the closure process. This increased the likelihood of individuals transitioning more than once. One interviewee shared,

“...a lot of the family members that we were talking with, some of these folks were elderly. And all of a sudden you're talking about uprooting their son or daughter or brother or sister and they are scared about this transition, but then you have got all these people calling and giving them different information and making different statements...So unfortunately because of the misinformation they received and they are hesitant to engage in the process, the family member is going to have to transition twice”.

Communication lapses among system partners confused families about the transition and moving process. Families were getting phone calls, information packets, and word of mouth information from different sources, which led to confusion and sometimes misinformation. One stakeholder said, “PAS and JDC staff was calling families, causing a lot of miscommunication for the transition process.” One interviewee elaborated that JDC staff were calling parents and urging them not to participate in the ACCT process. On the other hand, respondents felt there was a lack of information provided to families in appropriate formats. One stakeholder explained,

“We relied on the traditional methods for informing families of what was going on and they were not sufficient because they were getting misinformation. They were getting wrong information depending who they talked to. They were getting information from the papers, from the union, from the parent association, from the staff, from our vendor, from the Division. They didn't know what was up or down. And they didn't know what was right or wasn't.”

“We did not have a focused effort to keep families informed and engaged. And what I mean by that is that we relied on the social workers at the centers. We relied on the PAS entity. We relied on local media. We

relied on what there was a Parent's Association and the problem was depending on which one of those people you went to, you got a different message. So it was very inconsistent. And so we said lesson learned... We have to come up with a more direct approach.”

“We relied on the traditional methods for informing families of what was going on and they were not sufficient because they were getting misinformation. They were getting wrong information depending who they talked to. They were getting information from the papers, from the union, from the parent association, from the staff, from our vendor, from the Division. They didn't know what was up or down. And they didn't know what was right or wasn't.” ~ stakeholder

This lack of a coordinated effort to educate parents and families resulted in families having a difficult time understanding how the closure of JDC could benefit their relative. One person said, “There is lots of information about how the parents and staff view the community and what they perceive as the dangers of the community and that information is just being spewed all over the place. Yet we have not, I think, found an effective way to give information to families about the positive part of the community.”

Additionally, it was expressed that there were limited opportunities for parents to sit and talk about their needs, concerns, and reservations about the closure process. This ultimately led to some individuals transitioning to another SODC due to family members feeling more comfortable with this type of placement for their relative. One interviewee elaborated that there were “...18 people, or 20 people, that parents just said we are more comfortable with an SODC.”

Family Mistrust

Stakeholders shared that they thought that families found it difficult to trust the information they were receiving from the State. They felt as though the information they were being told was inaccurate and misleading. Some families were so distrustful of the transition process that they refused to speak to CRA and nearly 70 of them reportedly formed a “do not call” list in an effort to not be contacted by CRA.

Stakeholders indicated that some family members felt as though their opinions were not being taken into consideration during the transition process and felt as though decisions were being made for them. One stakeholder shared, “I can tell you that the guardians openly spoke to me about how they felt like they weren't communicated with. They weren't allowed really to make the decisions for the people they cared for. They felt they were kind of pressured into this....”

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Gaining the trust of guardians typically took months. It was gained by being available to talk with guardians over the phone, return their phone calls, answer their questions, as well as by being forthright and admitting when CRA did not know an answer to their question. However, it was believed that once the trust of guardians was gained the parent group would actively try to sway the decision of guardians to be against the closure process, which only resulted in more confusion for family members. One interviewee said, “And then the challenge is after you get a family to consent and the parents group found out, they are in like in droves on this person trying to get them to change their mind.”

RESIDENTIAL TRANSITION

Barriers

Stakeholders shared that many families were skeptical about the transition from an SODC to a community-based setting. The idea of moving was overwhelming to guardians who worried about their relative's adjustment period. Some families had negative past experiences, resulting in a long and stressful adjustment period for their relative and hence worried that this transition would be similar.

"From the beginning they were skeptical because from what they had been told and their son is very young, early 20's. His first group home experience was really bad and that is how he ended up going to Jacksonville. And they were so skeptical and nervous because he had been so stable for so long under the structure and the constant redirection that 'Oh my God, are we going to have a repeat of what happened before and then you guys are going to say you can't handle him.' And so they just were really, really nervous."

"Because he was settled in there and whenever he moved it always took him months to get re-acclimated and I just hated to see him have to go through that again. It took him almost a year to get used to Lincoln. Well he was there 24 years. Well then they moved him to Jacksonville and he was 8 and 9 months getting acclimated there. But after ten years, he finally was settled in. He could go to his workshop and back home on his own and that was home to him. I just hated to see them disrupt him again."

Guardians were also resistant to the closure of JDC because they had been told that their relative would never be able to live in the community due to the level of care and attention they required, which, they felt, could only be provided within an institution. Thus, the idea of former JDC residents living in homes and integrated in the community required time for guardians to process. Acceptance of the process typically came when

family members were able to see their relative successfully transition into their new homes and adjust well. As one stakeholder explained,

“We have another individual that his sister I think she lives [out of state] so we had a lot of phone calls on the front end of it because again, ‘Do you really think this is going to work for [him] because I was always told he’ll never live anywhere but an institution-type setting?’ So it was a lot of that in the beginning and it probably was instantaneous two weeks after he lived here. She stopped calling. I mean she calls the house to see how he is, but her concerns I think really mellowed out some.”

Furthermore guardians wanted assurance of permanency that the provider they choose would be able to meet the needs of their relative and not get ‘kicked out’ if they were unable to meet their needs. Guardians also wanted reassurance that the provider they chose would not be out of business shortly, which would ultimately lead to finding another provider/placement, thus forcing their relative to move yet again. One person said, “There were families that were convinced that their son or daughter would fail miserably because the last four or five placements have been horrendous.”

Guardians also wanted reassurance that the immediate needs of their relative were being addressed, such as safety and personal care. Additionally, guardians wanted their family member to move to a location in which they would be closer to their family.

Pressure from the Jacksonville Community

Stakeholders indicated that the local community’s opposition added to families’ concerns. One person claimed, “You have a community that was necessarily opposed to the closure of JDC because they are looking at it from an economic standpoint.”

Another elaborated,

“The people living in the community. They were opposed to the closure due to primarily for economic reasons because when you have 400 pretty well paying jobs, you know the Chamber of Commerce opposed, economic development. The city politicians, the area politicians opposed closure. The local newspapers picked up on that.”

Press coverage of the closure through television and newspapers may have added to the parental and community opposition. One person recalled, “One of the disturbing things, I think that was disturbing and frustrating for us, was the constant negativism ... from press networks...here in our area most of the press was very, very negative.” Another stated that the press was “...very interested when there was a big story to splash across the front page.” Another stakeholder acknowledged, “I would turn the news in the morning. It would be like, ‘JDC is closing and all these people, they have nowhere to go.’” One stakeholder alleged,

“...they didn't show anything about the good of [the closure]. It was only one-sided. It was always negative. It was always about how wonderful JDC was and how great care they gave. This was the right place that they should live and they could get much better care than in the group home setting. It was very frustrating for us.”

“One of the disturbing things, I think that was disturbing and frustrating for us, was the constant negativism ... from press networks.” ~ stakeholder

Public Perception that Some Individuals with DD Cannot Live in Community

Community members were in opposition, according to some interview participants, due to misperceptions about the ability of people with IDD. One stakeholder said,

“[Community members] were extremely negative. They felt like [JDC residents] couldn't do anything on their own. You know the people who were uncommunicative, that they would never be able to learn any sort of communication no matter what kind of resources and tools we brought to them to help them become more communicative.”

“I hate to say that [Jacksonville] was un-savable, but just the attitudes that people in [Jacksonville] had about people with intellectual and developmental disabilities; that wasn't going to change.”

JDC PARENTS' ASSOCIATION

Parents of JDC residents felt a bond with each other and as though they needed to remain united during the closure process to advocate for the needs of their children. The parent group was described as having a hierarchy; the core group consisted of ‘officers’ whose role was to keep parents on track to do certain tasks. Parents felt as though they violated the group when they began making arrangements to transition their child into community living placements. One stakeholder explained,

“Within the hierarchy of the parent's group, you have a core group that I guess would be the officers of sorts and certainly they tried to keep everyone on track to do certain things and so people felt pulled. They genuinely felt pulled. They needed to maintain their pact with the people that were like them and that in some ways one family said ‘I feel like I violated the parents' group.’”

In fact, the Jacksonville Parent’s Association was described as purposefully misinforming families, as well as the media, about how the State was handling the closure process. The Parent’s Association, however, was also described as being ‘non-players’ in terms of influencing the closure process.

PERSON CENTERED PLANNING

Assessments

The Department of Human Services (DHS) contracted with Community Resource Associates (CRA), a private training and management consulting firm, to act as an independent party to assist with the development of transition plans as part of the larger ACCT plan to rebalance the Illinois IDD service system. As part of the transition process, CRA analyzed current and past resident records to determine whether or not

additional or updated assessments were necessary. The ACCT plan calls for assessments in 15 domains: medical, dental, nursing, physical therapy, mobility, psychiatric/psychological, community risk/monitoring, behavioral support, communication, occupational therapy, sensory, adaptive/assistive technology, home and vehicle modifications, vocational/meaningful life/community integration and person centered plan specific. The assessment process operated on three levels of intensity. The first level was screening and included document review and interviews with the individual and key supports. The second level, internal evaluation, could include the completion of new assessments and the gathering of additional/clarifying information. The third level, positive behavioral support plan/external evaluation, is used if the individual “presents with significant behavioral challenges that cannot be sufficiently addressed with simply making recommendations to the provider and requires a more detailed formal plan for behavioral support.”⁴

During interviews, stakeholders were asked to comment on the assessments used as part of the closure. Some JDC staff felt that it was unnecessary for CRA to do assessments. One person expressed,

“I think there was a lot of duplication between our assessments at JDC and the assessments that the CRA did. I think there was a lot of duplication there because CRA from their PCP's and from all the interviews that they did before the PCP's came up with their own assessments and to me they mirrored a lot of our assessments. So to me it was just a lot of duplication.”

Another person indicated that it was offensive to have a third party conduct the PCPs, stating,

⁴ Illinois Department of Human Services (2014). Active Community Care Transition (ACCT) Process Overview. <http://www.dhs.state.il.us/page.aspx?item=65961>

“We had a process and we were very good at it actually... we were doing a good job. So it was somewhat insulting to have people coming, telling us how to do what we have been doing.”

“There should have been way more assessments of the clientele within JDC identifying ... primary diagnosis...[and] their significant behaviors that needed to be addressed as well as medical complexities and I really believe that there should have been more of a holistic approach with identifying all of that, having the internal staff being more aware of what all of those needs are, drilling it down to even the functionality of each resident within JDC and taking more of a leadership role with the care coordination working with community providers and assessors and things of that nature as opposed to having a dependency on you know others coming in and trying to do all the leg work.”

One person expressed concern that the existing JDC assessment and the CRA assessments sometimes differed stating, “They wanted to do their own independent assessment, which is fine. However it was never reconciled with our assessment of folks.”

Positive reflections related to the assessment process were also offered. One person commented, “What they did a really good job of is going into the consumer files at JDC, trying to figure out what assessments were there, making a judgment about whether the assessments were adequate or not and then filling in where they weren't.”

RFI/RFA Process

Provider agencies interested in participating in the ACCT process were required to complete a Request for Information (RFI) and a Request for Application (RFA). The RFI/RFA process was designed to establish a baseline of the organization's currently existing services, agency capacity and limitations as well as clearly outline expectations. ACCT Provider criteria included obtaining licensure from the state of Illinois, adhering to ACCT's principles and values⁵, working with CRA on PCP implementation, obtaining expedited payment status, adopting a "zero eject" approach, participating in meetings, training and data collection, and signing a Provider's Pledge⁶. One stakeholder commented, "Originally one of our concerns was not having enough central Illinois providers that would be willing to support people in central Illinois. It turns out we did." Another reported that approximately 42 providers participated in the process, stating, "As a matter of fact, one of the great joys ... is we started with about 20 providers at JDC. We actually ended up with about 42 providers when we finished with JDC, but only 13 ended up taking people." Another said, "We made it a process that it was not exclusionary. Anybody could submit."

"Originally one of our concerns was not having enough central Illinois providers that would be willing to support people in central Illinois. It turns out we did." Another reported that approximately 42 providers participated in the process, stating, "As a matter of fact, one of the great joys ... is we started with about 20 providers at JDC." ~ stakeholder

A couple of providers, who did not participate in the ACCT process, expressed frustration that their organization's information was not being shared with the guardians of potential residents. One said, "Some heard about us through other families that had like a parent's group and I know once we got in with some of the parent group then our

⁵ ACCT Principles and Values: <http://www.dhs.state.il.us/page.aspx?item=67482>

⁶ How to Become a Provider in the ACCT Process <http://www.dhs.state.il.us/page.aspx?item=66097>

name kind of got spread around.” One provider described a situation in which a guardian reached out to the agency,

“We even had a guardian that came in from [another state]. She flew in to tour and we found out she was touring another home that day. We happened to get a call ... and they wanted to know if I could show her. ...We did the tour...she is like, ‘Oh my God...if I hadn't toured, I would have never ended up with you guys. I would have ended up with someone else.’ Because it was almost like if we didn't advocate for ourselves, they didn't know we existed even though we were being told they were given options...Our name wasn't given to them as an option. And I think we ended up with four individuals that had no clue we existed until the very end...To us that was very frustrating because we were being told all along that they were given choice.”

Person Centered Planning Meetings

In addition to completing assessments, CRA facilitated person centered planning (PCP) meetings using one of the following approaches: Authentic Person Centered Planning, Essential Lifestyles Planning, MyPlan/WRAP, or Support Circles. The PCP process began as JDC residents were scheduled to move out of the facility. Generally, most stakeholders had positive comments about the PCP process and outcomes. There were many stakeholders who expressed that PCPs were done well and they were happy with the results. One respondent stated, “I think the assessment and the person-centered plan writing were done extremely well. I think we really looked very carefully at what every consumer needed and I think in just about every case we provided the whole process

“I think the assessment and the person-centered plan writing were done extremely well. I think we really looked very carefully at what every consumer needed and I think in just about every case we provided the whole process was very well done.”

~ stakeholder

was very well done.” A provider said, “I like the person-centered plans... I thought that they were thorough and really gave a good snapshot of the individual.” Regarding the process, one person said it was “...very respectful, very kind and really genuinely person centered.”

Stakeholders really seemed to be on board with the concept of person centered planning. One person mentioned, “I think the notion that we are finally asking people what is important to you about where you live and what you do. That we have finally found our way down that path is really significant.” Another person said, “It was a nice perspective to be able to see genuinely what they liked, what they did not like, things they found important in their life, their negotiables, their non-negotiables...”

One stakeholder described a PCP meeting,

“... family members would be there. Jacksonville staff would be there if they were willing which they weren't always, just to tell their story about the individual as well. And the individual was there hopefully. They did not bring them all the time. And they would do this large picture about what they saw their perfect dream home being like.”

Another stakeholder explained, “Well the ones that I attended were extremely positive, very supportive of the person. It was wonderful. I think that the person felt very much heard.”

Opinions about CRA conducting the PCP meetings were mixed. Some stakeholders felt that it was very useful to have an independent third party, while others felt that CRA was not knowledgeable enough about the individuals.

Several stakeholders expressed satisfaction with the use of an independent third party to tackle transitions. One stakeholder stated, “I think using a third party was really smart frankly. They did a good job...I think it lent some objectivity to the process that we might not otherwise would have had.” One stakeholder stated, “I found them to be extremely responsive and helpful. I mean I would pick up the phone and call [a CRA staff] on his cell if I needed something and he would answer. So I felt like if we asked and if they were having trouble getting something, they would let us know or connect us with the right person as well.” Another said, “They were genuine. They were honest.

They wouldn't sugar coat anything.” One interviewee concluded, “I think a lot of the times it was easy for CRA to be the scapegoat.” Similarly another alleged that, “CRA became the whipping boy,” and was blamed for steps in the process for which they may have been responsible due to the illusion of them being in charge.

On the other hand, some stakeholders critiqued CRA. One person explained, “I don't think [CRA] had a good understanding of the clients that they were trying to get out into the community because I guess if you are going to form a team of people that are going to be discussing their clients, it should be people that have worked with the clients for years and understand their history and understand the program instead of hiring people from outside. It would be like, ‘Oh, come on in and make this plan about what is going to be the best interest of a person they barely know.’”

“...if you are going to form a team of people that are going to be discussing their clients, it should be people that have worked with the clients for years and understand their history and understand the program instead of hiring people from outside...” ~ stakeholder

Some stakeholders didn't agree that CRA had the proper perspective for the process, stating, “The choices were being made by individuals who had predetermined philosophies in their head that everyone should be in a community setting and that state institutions were bad.” Others felt that CRA staff thought, “We're here to save you. You just should be thanking us instead of whatever.” Some felt they were not realistic and said, “...sometimes, I think, when they presented information it was a little too rose-colored.”

Not all interview participants shared the positive feelings toward the PCPs. It did not appear that everyone understood the philosophy behind the process; specifically since the process was focused on goals and dreams and not just clinical objectives. One person said that the PCPs were very lengthy at first but started to become shorter

and more realistic as time passed, “But the very first ones, the ones I was involved in, they were extremely lengthy. We're talking about having to sit for three hours ... they started to get maybe a little bit more realistic...” One stakeholder offers a possible explanation,

“... we need to further define person-centered planning because it really is an open-ended term. People define it as what they define it as. You know people decide well that it's person-centered because the person was in the room and I meet with them every year and this is what we decide for them. So we involve them in this process. Person centered to me is a more global approach. It's about building services around a person rather than plugging a person into services and the state of Illinois has a long history of plugging people into services whether it be in the community based provider model or SODC's or ICF's.”

Some stakeholders indicated that there were two transition processes co-occurring.

“...we had a parallel process going on at JDC ... the JDC personnel, their case management, social worker crew ...were doing their own discharge process. So if they didn't like [CRA] or if they didn't want that person in [the ACCT] process or whatever then they would go out and find a provider and just move them. And so people were being literally yanked out of [the ACCT] process and moved.”

Another person noted that disagreements by some staff with the emphasis on moving people to smaller settings,

“...basically what we found out was that there were a couple of the [JDC staff] who really, really disagreed with what [CRA was] doing. Because [CRA] had ... the expectation that nobody moves to a facility or home [for] more than four people.

RESIDENT INFORMATION

Jacksonville residents' information was a critical piece of the closure of JDC. The information given to providers, however, was often incomplete according to some stakeholders. A majority of stakeholders indicated a variety of issues with the availability, quality and potential sabotage of resident information.

Providers explained that many of the JDC health records were out of date and “did not reflect an accurate portrayal of what the current medical needs were.” One person commented that the longer the individual had lived at JDC, the more likely the records were to be out of date, from a few months up to 20 years. Providers had difficulty obtaining original Medicaid cards, Social Security cards and state IDs as well. A variety of information appeared to be missing, including medical and behavioral records as well as the individual service plan. Some stakeholders indicated that they received plenty of information for medical, psychological, or social history records while others complained that they had not received enough important information in that particular area. For example, one person said that missing information had created difficulties in meeting the resident's medical needs,

“Basically, we weren't aware of a particular condition that he has and it wasn't in any records that they sent us and the records that we saw, you know, were only from the last year and a-half to two years. These are some things that were unresolved four or five years ago that we had to work through the guardian, we had to work through former healthcare providers to get information and, like I said, it wouldn't have made a difference in terms of our decision to admit him or not. But it certainly would have helped us manage his behavior a little bit better essentially.”

Many stakeholders noted occurrences of receiving misinformation about residents' data. One stakeholder described that “the persons' medical needs were much greater than what had been presented to them.” A large number of providers and JDC staff expressed that they felt CRA seemed to downplay the severity and/or

occurrence of behaviors or medical conditions of the residents. One provider described two relevant situations,

“We had screened several people from there and in the packet it said that she had property destruction, things like that. But it didn't go to the extent of what the property destruction was”

Other stakeholders indicated that information about the residents was withheld or difficult to obtain from JDC staff, CRA, families and others. One person stated, “There was one gentleman in particular... I didn't even know he worked for JDC. But once I found out he worked there, I've known him since childhood and that's the only way I really got some good, accurate information.”

Some providers mentioned that when they approached transition staff at JDC or CRA with questions about resident information, records would not indicate any of the issues the provider was experiencing. One provider said,

“And I would go to these meetings and these guys from CRA were going, ‘We don't see that behavior.’ I'm going, ‘I am not doing anything special here. I see it regularly.’ And they go, ‘Oh no. It's not recorded in the records at JDC. It is not happening.’”

Other stakeholders expressed that some JDC staff over-embellished the severity of residents' behaviors or medical conditions. One person stated, “...[JDC staff] said everything negative they possibly could say so as a provider you would go, ‘Oh no I can't take that person. The only place this person could be is in a state institution.’” One stakeholder commented, however, that JDC staff were asked by an unspecified source to remove negative information regarding behaviors from files to increase the likelihood and speed of placement.

Many behavioral support plans for individuals transitioning out of JDC were out of date or not practical for community living. Furthermore, the behavioral support plans, participants felt, were archaic, restrictive, and did not promote choice nor provide stimulation for the individuals. Agencies were under the impression that they would be

able to use existing behavioral support plans and adapt them to be used in the community, but found this was not often possible.

“Originally our thought was is that folks were not going to need very sophisticated behavior support plans. ...We were under the impression that the behavior support plans that were in place were essentially functioning and were going to be able to transition to the community with minor modifications. So our intention was that we were going to make some suggestions for how those could be tweaked to be used in the community. Shortly after arriving and starting to do reviews of the behavior support plans that they had in place, we discovered that there was virtually no way that those were going to translate to the community. The community wouldn't be able to do it because of restrictions that the community is under such as not restraining people when they choose not to do something. There were some practical implementation issues. We are not going to walk around with M & M's in our pockets all day long to hand to somebody every time they say 'Please' or 'Thank you.’”

Although there were many accounts of information not being complete or accurate, there were a few stakeholders who expressed satisfaction with the amount and quality of information provided to them. Some indicated that they reached out for staff information along with the packet information they received in order to get a complete understanding of the resident. They said this was very helpful. One person said,

“...I relied a lot on the information JDC gave me...I felt though that JDC staff in our transition meetings gave a lot of good information when they would come and I really relied on them most of all because as we were going through this process and as they're explaining dietary things, behavioral things, just different aspects of that individual, the staff can jump in and say, 'And by the way, this is a quirk that person has or you know they say this is what you know he likes, but he really doesn't like this

kind of food type of thing.’ That is what helped me the most was talking to the staff of JDC and people from [organization] who had worked with that individual before because then I can see it from a personal standpoint as well as from the paperwork itself.”

There were a few allegations of sabotage among stakeholders, who alleged that JDC staff were intentionally withholding information in addition to shredding information before it was available for copying. One stakeholder said, “Although programs were written and medication administered based on their programs, the actual [detailed] data for the programs was not there.”

Another person indicated that missing information was not pervasive, “Staff not sharing information with us or conveniently leaving stuff out was for a small number of people, but the people it happened to was for people that could least afford for that to happen.” Other stakeholders expressed that they didn’t think that the missing/incorrect information was a deliberate attempt at sabotage. One stakeholder mentioned that there was no evidence of sabotage occurring other than what people said they witnessed. In fact one commented that despite some issues,

“...the vast majority of the people were professionals... We had people especially towards the last couple of months that were there ... start saying, ‘Let me come over and talk to you. I've got some things you need to know.’ Or, ‘Well this isn't going to show up in the record because nobody thinks it is important enough to document, but you need to know this.’”

A stakeholder gives a depiction of how sabotage may have been perceived among system partners,

“We had one lady who went to the community and just was not doing well at all. She just had this huge problem with food at the community... And when we went into the home and did an assessment, she would see food on top of the refrigerator and she would go after it and become aggressive

and get anybody in her way. And then they said that Jacksonville did not tell them about that. Well guess what? At Jacksonville the food never sat on top of the refrigerator because there were never a refrigerator at the center and if there was, it was put away. So people just had different opportunities and behaviors and CRA did a good job of referencing each and every thing with saying, 'You may see behaviors that haven't been experienced.' They knew that from their previous experience in other states."

One CRA staff person explained that providers were claiming that they were experiencing resident behaviors that were not listed in the information packets,

"Then there were other behaviors that didn't exist in the institution that now were showing up that were behaviors from 25 years before because the person is back in a setting that scared them... Whether or not it's a noise from a car backfiring. We have found all kinds of things that people are experiencing now that have brought back other kinds of memories that people are dealing with. It's fascinating. And I am imaging that in some of those cases I am sure there are accusations of "Well you didn't tell us that this happened." And so that is how that is interpreted."

Participation of JDC staff became limited as their numbers decreased over time. A large number of stakeholders indicated that the departure of JDC employees throughout the closure process had a significant impact on the PCP process in that staff members familiar with the individual may not have been in attendance at the PCP. One stakeholder stated "... some of the staff that knew [resident's name] well were no longer employed there. So they were not at the meeting."

Despite such statements, the majority of stakeholders indicated that JDC staff who were involved in the transition process tried to provide as much resident information as possible to the providers. One stakeholder said, "All we could do was to make sure that everything was included in that transition plan and that all the information was given to the provider and just hope that they could sort it out." Another

stakeholder shared that JDC maintained their professionalism and “held their heads up” throughout the process. Another recalled, “They were responsive when we called, but I won’t say it was great. I know you had the mix of ‘Hey, I’m losing my job, but I want to see these guys taken care of.’ So I mean there were certainly many mixed emotions.” Yet another offered praise, “I think the staff at Jacksonville did a remarkable job. I mean just remarkable...” Additionally, a stakeholder stated, “...a number of them really rose to the occasion even though they were losing their jobs, seriously. They were committed to the individuals.”

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~ stakeholder

IMPACT OF CLOSURE ON JDC RESIDENTS

Some interview participants noted that the closure appeared to be difficult on current JDC residents. One stakeholder commented that when JDC was visited during the closure, residents would state, “We’re losing our home. Where are we going?” Another stakeholder explained that residents were feeling excited to move so it “got harder and harder on people who weren’t leaving....Four months into it people were coming up to us and just ‘When am I getting out of here?’” A guardian who was interviewed explained that their relative had been in one of the last groups of residents to move out of Jacksonville and meanwhile had been moved a number of times within the JDC facility to allow certain buildings to be closed. This guardian expressed “... he’s older and they moved him to two or three different buildings there in Jacksonville. The last couple of months they were downsizing and they kept moving him. And that upset him.”

Interview participants indicated that an effort was made to place people together in the community who were thought to be compatible. For example, one stakeholder

stated that a list of potential pairings based on friendship and compatibility was provided to CRA by JDC staff in order to better place people in a supportive environment. After CRA found available residences, they started pairing compatible individuals and filled the homes that way.

PROVIDER PERSPECTIVES

Provider Meetings

Several stakeholders talked about the weekly provider meetings which were held at JDC. One participant described, “It’s purpose [was] to update the providers on any changes in our process or procedures, to keep them up to date as to where things [were] at.” Another described,

“At the provider meetings there may be 15, 18, 20 providers in attendance and they would present four people, five people per meeting. And on a good day fifteen providers would all agree that they could serve all these people. What happened after that is anybody’s guess because [CRA was] supposed to then go to the guardian, give the guardian equal information about all 15 providers and then the guardians from there would choose and they were supposed to get back to [the provider] and say well the guardian would like to see you. And that process never seemed to happen. At least not with us.”

“We would invite each week providers who come to a meeting at Jacksonville or plug in by phone where we would share a little profile about the person and then they would have a sheet and they would say, ‘Yes I am interested in learning more about this person’ and if that was the case, we would gather that information, share that list with the guardian, get consents to share their packets and then move forward with that.”

Another said, “...it would be kind of just be an overview of the person’s likes, their dislikes, what type of setting they would like to live in, their geographic preferences, [and] what their family’s preference was.”

The method was critiqued by many participants. One commented,

“...the way that the cases were presented to providers at the provider meetings, it was like an auction and they were presenting what they learned in their assessment... At first they were like, raising their hands and different providers were saying they were interested in interviewing and meeting the person or reviewing the records. We really didn't like the process and finally we were able to get them to alter it by at least having a silent ballot. So it was more like a silent auction. It was still an auction.”

“You had a choice of three providers, but they would always say the preferred provider is the [provider who can provide care in] one month.”

After receiving criticism, the process did change. As one interviewee described, “We thought it [the initial process] was not very dignified for the individual. But they got it. And they changed it.”

Choosing a Provider

One stakeholder explained the process by which guardians were approached by the PAS agency and thereafter made their decision, stating that the PAS agency would

“...call the guardian and say, ‘These three agencies have come and visited your loved one. Two of these three have said that they would like to support your loved one. We need for you to make a choice about which of these agencies you would like to have your loved one go to for pre-transition visit.’ At that point the guardian can call the agency directly. They can ask what the person knows about the agency. The PAS agency is supposed to be neutral, but they could ask us what our experience is or they could ask [name] what [their] experience has been just in the past. And then the guardian makes a decision. Once the guardian makes the decision, then the pre-transition visits can be planned.”

A stakeholder explained her perspective on the significance of completing pre-transition visits,

“...I would say, ‘I always like to look at several places. It’s like when you buy a home. When you walk in the home that is going to be your home, there is just something you know it’s the right home. When you go away to a college, you know when it is the right college.’ You can’t explain it. It’s just like a gut feeling and I think when you visit different facilities that will happen.”

Stakeholders relayed families’ discontent with the availability of residential providers within their desired geographic area. “Everyone is wanting them to be back closer to their parents, to their family, to their natural family. We just haven’t succeeded in that yet,” said one stakeholder.

“Everyone is wanting them to be back closer to their parents, to their family, to their natural family. We just haven’t succeeded in that yet.”

~ stakeholder

Despite this, stakeholders in general expressed satisfaction with living arrangements. For example, one person was impressed, “It is a brand new house, ranch style, a large living room in it, dining, kitchen area and each one of them has their own room with a small TV on the wall and there are two humongous bathrooms.” That person also went on to explain that, “...when they pulled in the driveway [of the new home], she got him out, he walked right up, opened the door and went right in like he knew that was where he was supposed to go.”

Moving Day

One stakeholder explained the steps taken prior to an individual leaving JDC,

“...We are going to make sure that the provider is ready. The transition process has been done. The assessments are completed. That the staff have been appropriately trained for any things that needs to be, the behavioral support plans are in place. Whatever it is that needs to be there to make sure that the individual has far as we can tell what is necessary for them to be successful in that community transition.”

Moving day seemed to be a different experience for each resident. One person said, “They were nervous. They were anxious. They were certainly all over the place. You know just checking out their surroundings.” Another stakeholder expressed disappointment that moves transpired differently than was typical, “...normally when a person leaves ... there is a goodbye party ...”, although this did not appear to be the case during the closure. Providers, on the other hand, tried to make it a smooth experience. Another person said, “...we did special things...one guy [was] moving on his birthday and we were nervous about that. So I actually had bought a birthday cake for him... At his new place they had a cake there and people were there to have a party for him so that went well.”

Nearly all stakeholders expressed safety as the number one priority; however, moving days were described to be hectic and/or disorganized. One person said that if a provider was not ready to accept an individual, that provider wasn't going to let the individual move for safety reasons. They explained that, in some cases, the provider's staff may not have been trained or obtained the necessary home goods or medical equipment. One stakeholder explained that they had to,

“...halt the move because the provider didn't have a lift to get them from their wheelchair into bed or to get them from the wheelchair into the bath tub or they didn't have the mats next to their bed in case they rolled out or you know just something simple like they had requested to have bright colors in their room and that didn't happen.”

One stakeholder explained that they thought the move was “reasonably well-planned” and that JDC staff had compiled a list of all the person’s belongings and residents were asked to help with the packing. Another stakeholder, however, expressed concern with the quality and amount of the items residents brought with them were lacking.

Some stakeholders told stories of residents showing up with little to no clothing or toiletries, causing providers to go shopping for those items quickly after the individuals moved in. One person explained that they had kept receiving more clothing and items as the closure continued, but that these items did not belong to whom they were sent, “It was somebody else’s. You could tell because the initials that were written in it didn’t match his.” Alternatively, other providers explained that the residents they received had average amounts of luggage upon their arrival.

Aside from belongings, stakeholders expressed concerns over the amount of cash the individual arrived with, “...the most I’ve seen anybody arrive with was \$30 or \$40,” said one provider. Another person commented on the confusion the individual experienced while waiting for their personal funds to transfer from JDC to their new home. “... you have the individual saying, ‘But I have money. I have a lot of money down there. Where is my check? I was working ... where’s my checks?’”

One aspect that stakeholders thought did not go well was the physical transition. This included the lack of information provided by the JDC staff as individuals were dropped off. One said, “[they] didn’t say anything, no advice, no ‘[this individual] needs a wedge on his bed.’ We had no clue. That wasn’t brought up.”

Some respondents reported individuals were dropped off quickly with no attempt at acclimation. Specifically, one provider explained,

“This is the most disappointing part to me. When they arrived at my facility, here I am opening a brand new beautiful house and nice neighborhood and I am there. My staff is there. We are ready to welcome them. They arrive in a van similar to ours. All of their belongings are in trash bags, some of which they don’t much in them at all... [JDC

staff] didn't participate in any of the trying to get them acclimated or they were, 'Okay, we'll see you.' And that was it and they were gone."

Another said, "... they dropped everything off at the house and I kind of expected the case manager to be at the house that afternoon to like, help us with stuff. Basically they dropped everything off and they said, 'All right, see you later.'" Another stakeholder commented,

"...staff ... didn't stay for a long enough period of time. I mean ideally you would stay a while and help them get settled in, make sure that everything was in order before you left and that the new staff had all the information they needed. We sent packets along with them, but what happened was they just dropped the person off, handed the packet over and they were gone to the next stop you know to drop the next person off."

Provider Readiness

Providers expressed that it was somewhat difficult to be fully prepared for the new residents before the move-in date. One provider, who was building more homes to accommodate larger numbers of residents, described their preparations for the transition. One said,

"...there was a lot of struggles of trying to obtain houses that we had to completely modify and make them handicapped accessible with furniture, all the electrics, cable installed, telephone and when you are being rushed it was a lot of quick, quick fast changes."

"...we hired as soon as we knew we were going to be building. We hired staff. So we went like three or four months training staff where others pulled them off a week before. But we thought it was going to be too much stress for the individual and for the staff to try to bring them into that setting. So by the time the residents came to us, they had staff people that had worked in a building, been completely through DSP training and

knew all of the policy, procedures and we even made cheat sheets about that person, what they require for each individual so at a quick glance they could look and see, okay they need this and this and this or they do this and this and this without having to go to a file and look it up.”

A stakeholder who was involved in the moving process explained one situation that occurred in which a provider was not ready for an individual to move in,

“... I do recall one problem where the community group home wasn't logistically ready for the person when they got there. It doesn't mean they didn't have beds and chairs and desks and kitchens and stuff like that. Staff just weren't ready when the person got there and we were pretty annoyed at that provider.

POST-TRANSITION FOLLOW-UP

Participants were asked about their experiences with post-transition follow-up services. They identified a few different organizations/agencies which they had interaction with during the post-transition follow-up. They included: CRA, PAS agencies, and the Illinois Bureau of Transition Services (BTS) within the Division of Developmental Disabilities/ Department of Human Services (DDD/DHS). Both CRA and BTS post-transition roles were to conduct weekly face-to-face visits for the first 8 weeks following the move out of JDC and then monthly face-to-face visits after the first 8 weeks for the first year⁷. In addition, PAS agencies conducted weekly visits for the first four weeks following transition. Regularly scheduled quarterly visits began immediately following.

Some providers indicated that there were a large number of agencies checking in with them regularly and it became confusing as to who was overseeing the individuals'

⁷ Illinois Department of Human Services Division of Developmental Disabilities (2/6/2012). SODC Implementation Outline & Key Features Plan Elaboration. <http://cgfa.ilga.gov/upload/SODCImplementationOutline&KeyFeatures02062012.pdf>

outcomes. One provider said, “They followed the individual afterwards to the point where there were so many agencies coming in and out of here. I didn't know who was who for a good two months.” Another individual explained, “...it was hard to keep in contact with them because we always got passed along, and so that was hard because I never really knew who the contact was because when I would get ready to contact them about certain people, it was always, ‘Hey we've been moved, or ‘Hey I'm not assigned to your case anymore.’ So that was hard for us.”

One stakeholder said, “...it was almost like there were too many cooks in the kitchen at times.” Another stakeholder described,

“The [follow-up] system doesn't really make sense... You have BQM, and it largely looks like institutional rules that they are trying to apply to a community setting with another set of expectations and rules that these people are going to be following an in person-centered plan that helps people have real lives in the community. And then you have got these other people going, ‘No, no, no don't do that.’ And then that is too many risks and that is too much trouble and another group is saying, ‘That's not in your funding.’ And another group that is going, ‘Well you have to do this in order to prevent the problem.’”

While many providers noted a high volume of follow-up traffic, others described a lack of follow-up services that they received. A few providers described CRA as being inconsistent in conducting follow-ups. One provider said that BTS, on the other hand, was consistent in conducting follow-ups. Improved coordination for community monitoring between entities was suggested.

Stakeholders expressed a few possible reasons for why follow-up services may not have been provided as expected. One individual expressed that lack of funding could have been the cause for the decreased or missing follow-up services, “[CRA] isn't following up anymore because they don't have funding”. One stakeholder described their experiences of providing follow-up saying, “We were so short-staffed that we had to decide who is more of a risk right now that needs to be visited, and who can go for another week?” One person said, “We were just told we didn't need to do them

anymore. There were people that were only on their third, fourth week of visits and we were told to stop and that was it.” Another individual stated that they “...were doing [post-transition services] for gratis because they never figured out how to pay us for that.”

A couple stakeholders described the post-transition follow-up services as beneficial. One person said, “I think that the follow-up was pretty good. I felt like, you know, people were even a little over-kill. I mean in some cases we definitely needed some support just to make sure we had everything in place. But I thought it was good.” Specifically, BTS received praise for their work. One person said, “[BTS staffer], she's been following everyone, coming in and checking on them to make sure the transition was good...she was really good to work with also.” Another commented, “BTS has been here every week like I said working right alongside us. They have been absolutely supportive and wonderful, honestly.” To the contrary, another stakeholder said regarding BTS, “It is not seen as being a support to the providers” while another said, “The part of the Division that is supposed to be the one that works most closely with providers and has providers' back is not trusted by the providers.” A stakeholder explained,

“when a provider is overwhelmed or they got in over their head and they didn't realize they were in over their head. But they are afraid they are going to be in trouble with the state if they go, ‘Oh my God, I am floundering here.’”

Another recalled, “You know quite honestly, it was often difficult to get a hold of anyone at the Department. You know you finally started just researching it yourself... I think that communication was difficult many times because they too had a plate that was full.” Some follow-up service providers indicated that they did not possess the authority to make sure providers were following the rules and providing adequate care. One individual stated:

“You were told to make sure those things were happening, but we were given absolutely no power to do it. And the providers knew that we had no power.”

“We don't have a clear resolution on responsibilities for post transition and who does what when. And [what happens] when there is a brewing crisis, or there is a provider not following the person-centered plan or the recommendations, or they water it down into their ISP so that they are only minimally doing what was recommended.”

Individual Budgets

Responses were mixed with regard to the adequacy of the individualized budgets prepared for those transitioning out of JDC into smaller community-based settings. Many interviewees indicated that they felt the rates were fair. With regard to the flexibility the rates allowed, one interviewee said, “...we would not have been able to serve those individuals with the high medical and the high behavioral needs had we not been able to get a rate to operate it the [way] we did.” Another person commented, “So you had the flexibility of just having the two of them in the four-person home for a short time to kind of acclimate. That's great. And it was only because of the accelerated rates. And that is the only reason it's possible.” Another shared their experience with the expedited speed in which rates were revised, “...rates were tweaked very quickly,” and another agreed, stating, “...we were getting rates back within 24 to 96 hours sometimes. That part worked and has continued to work...” which also allowed for service flexibility and response to changes in service needs.

Others, however, expressed concern over the long-term viability of the rates. One person said, “I think the concern again from a provider perspective is, ‘Well how long is that going to last? If I need that support for four years, next year ...’”. Another interview participant stated, “DHS is always [using] the carrot and [the stick]. ‘Okay we are going to give you all these things if you take these individuals.’ And everybody was kind of sitting there going, ‘Yes I will believe it when I see it.’”

Concerns about the viability of smaller settings were expressed. One person said, “When we started this process, we were kind of nervous on the financial side

because we knew from past experience that a four-bed home was a money loser.”
Another said,

“One concern that I know I have as a provider, and many others do too, is the rate going to remain the same? I mean, because I would say that makes a difference on how many people you got to have [living in the home]. For instance, [for] each one of these individuals the rate is about \$115,000 a year. And they are one to one with the exception of night hours. So with that increased staffing both at the day training and at home, if the state were to come back next year and say, ‘Sorry, not giving you the one to one funding anymore’, then it would definitely have to be at least four if not five or six [people per home].”

Uncertainty of Rates

With respect to the unknown viability of the individual budgets, one stakeholder indicated that the State was aware of provider concerns and said there was,

“...a great group of providers in Illinois that have really taken a big step, particularly given the state's history for not paying rates that have been high enough to support folks or the delay in the payment cycles or all the other things that providers have a reason not to trust the State on.”

In response,

“[DHS] created some incentives for agencies to support at least eight persons [total]. We give them some enhancements and rates. We put them on an expedited payment. We gave them some cash flow incentives. We gave them some additional resources and start up monies and life safety and accessibility dollars to incentivize providers to take at least eight persons.”

It is possible that the process was confusing to some because some of it was new. One person commented,

“A lot of that early work was developing actually what we wanted to see and working on a new rate structure. Not the technical aspect rate structure from how we could fund this, but how we were going to request the funding and how we develop a model for approving advanced budgets or pre-planning budgets.”

“... in order to do the individualized budget for everyone, we have to do a budget narrative that basically takes that summary and puts it over here in this other thing and it says this is all the stuff that the provider is going to have to do and then that gets translated onto a calculations sheet. So we literally go they are going to have to do this. That goes over here on this line. We're going to have to do this. That goes over here on this line. Oh that's already covered by the first line. Okay so we do this calculation sheet that we then submit to [Division staff] who then walks that through with the budget people.”

Given this sentiment, it is not surprising that others shared frustration with the process. One person mentioned, “It was a paperwork and funding nightmare...”, while another said, “First of all, it took a while for that whole ‘how were they going to figure out the funding’? and that was people ... with the Department of Budget and the Rates Department...” There also seemed to be some confusion about how to complete documents related to funding. One person stated, “Providers again were not given the correct information. They didn't realize that they had to do a regular funding packet.” Another shared optimism about the enhanced rate stating, “...I hear it probably two to five times a week ... that the governor is committed to the idea and the Division is committed to the idea and the Department is committed to the idea that the rate is the rate. They have to do a rate on a yearly basis. But unless the person's needs change, the rate is the rate.”

Frustration due to perceived inconsistency was also expressed by other stakeholders. One said, "It is hard to manage in the financial and finance department. One day ... this person is getting \$55,000. No tomorrow he is getting \$75,000... You know it's back and forth. So it is hard to budget." Not everyone perceived this as inconsistent. As another stakeholder commented,

"So at the time the person was ready to begin their pre-transition visit, they didn't have a final rate...But people were willing to take people because they knew this was the range that we were talking about and the level of supports. I think it was brilliant because it didn't slow down the process. And people criticized the fact that people were on pre-transition visits for a couple of months. I'll tell you what it allowed. It allowed us to get people moved quickly, safely and correctly. And the provider was able to see what supports the person needed, to look at the individual planning budget that we put together, to look at the planning budget... and then once the person was there, then it became the rate."

Despite the enhanced rates some providers, particularly new ones, were apprehensive about making such large capital investments. One stated, "We had nothing and we were opening houses from scratch. We don't have vehicles. So even the enhanced rate is really not enough to open a house and get a vehicle and all of that stuff."

Though the transition plan was developed by CRA and the rates were set by DDD/DHS, there was still confusion about how rates were developed. One person stated,

"We are still negotiating some of the rates because I don't know how the department came up ... mainly day program rates because some of them came back with an enhanced day program rate of like \$19,000 as opposed to the \$11,000. Some came back at \$12,000. Some came back at \$13,000. Where did these come from? Who sat down and decided that this person was going to get a higher rate than another person. So we're still kind of negotiating some of the day program rates and then the bad

part was that as of October 1st everybody got the 5% increase to the whatever portion of the rate that was enhanced and was increased. And so they re-ran new sheets and when they re-ran them some other things that we received previously weren't on the new sheets so there was a lot of confusion.”

Others perceived friction between CRA and DDD/DHS,

“DHS's office is often so resistant to change. It was almost like [we] were ... butting up against the system. ‘Well here is how we run rates.’ ‘Well we can't do that because the rate machine doesn't work that way.’ ... I felt like there was a lot of not necessarily negative conflict, but conflict because CRA wanted to change the world and DHS was still sitting in their bubble going, ‘Sorry this is how our machine works. We can't do it that way because we can't calculate it out like that.’”

A few interviewees expressed frustration about the payment backlog. One said,

“...we are supposed to be receiving expedited payments and we haven't got a dime yet” and another commented, “Until we get paid, I have no plans of doing another one.” A third stakeholder stated simply with regard to the rates, “It is a leap of faith on the part as a provider.” Another person commented that the current payment system hinders expansion, “... \$300,000 for a house? ... If the person doesn't like me, they can leave. I am still paying the money. I'm still buying this place. ...I am supposed to go back to a local bank and say I have \$300,000 in IOU's from the state of Illinois. Would that be good enough for a loan?”

HCBS Waiver Program

A few respondents indicated the need for system change in Illinois related to the size of its Medicaid HCBS budget. One said, “In the old processes, the rates weren't the best. Even with the new process, the rates probably don't match up with other states

that are fairly successful with this journey that we are doing.” Another stated, “...we have a long way to go with the rate structure.

Even with the new process, the rates probably don't match up with other states that are fairly successful with this journey that we are doing.” Another stated, “...we have a long way to go with the rate structure.” ~ stakeholder

Low DSP Wages

Some stakeholders indicated a general community provider need to increase wages for Direct Support Professionals. One person said, “We are paying them less than \$9.50 an hour and they can't afford health insurance and retirement.” Another commented, “. “Do the math. It's about [a] 50% turnover rate. They are not getting paid a living wage that keeps them from going somewhere else.”

Bureaucracy

Finally, Illinois' bureaucracy, was mentioned by several interviewees. In some cases, regulatory bureaucracy confused the process. One person shared,

“...the weird thing is that the person who [has] the responsibility for something may not have the authority to actually make that happen. And the person who was the identified leader or the person who really had the ability to make those directives often chose to say let's talk off-line. So we had no idea what was actually being resolved or not being resolved within the bureaucracy itself.”

“I do think Illinois takes bureaucracy to a whole new level... it's an art form. It's a tragic art form, but it's an art form. You've got rules about how you can make rules and whether you can talk about having made the rules

and whether or not you are allowed to even review the rules and does that really exist as a rule or is it just in a memo and does the memo qualify as a rule or is it the enforcement of a rule or is the policy an interpretation of a rule or a law and if it is does it carry the same....”

“I do think Illinois takes bureaucracy to a whole new level... it's an art form. It's a tragic art form, but it's an art form.” ~ stakeholder

COMMUNITY CAPACITY TO SUPPORT TRANSITION

Another key area of concern reported by stakeholders during interviews was community capacity to provide services well. For example, one person stated,

“We have to build the community to support the people that transition out of Jacksonville Developmental Center or any other center. But we look at it as a good investment of resources and time because the infrastructure we are creating to support folks coming out of Jacksonville will be the same infrastructure that will support folks coming off of *Ligas* or off the PUNS list as time moves on.”

Another person commented, “We're hoping that most of [the money used to run JDC] will get redirected back into developmental disabilities.” Another said,

“...if we can shift those dollars out of the Centers ... to enhance the provider networks ... to build collaborative networks, to build infrastructure in those areas, that is not only a good investment for the folks coming out of [an SODC], but it is also a good investment for all the families that have family members living with them that need to move from their family home into the community or out of the ICF's and nursing homes as part of

Ligas... So ... the resources are really going back into building a more robust system that can support more of the population versus a few.”

Another comment made regarding the shifting of resources as a result of rebalancing was,

“Where is the money going to come from to pay for that? ... It's coming from JDC because it was \$210,000 a year per person. Now I am only paying \$100,000. I got \$100,000 left over. Okay? That \$100,000 is what funds any enhancements to the rates or any infrastructure or crisis system or medical services... but I don't get that until the Center is closed.”

Another interviewee commented, “We are trying to create infrastructure to support folks as they transition and some of that infrastructure has been underfunded or not funded for many, many years and is kind of over the last decade or so not that strong.”

The need for crisis services in the community was a general concern. One person stated, “...we don't have a sufficient crisis system. It's inadequate.” Another stated, “That's something that is very much needed... in fact all, most providers have pleaded to make sure that there's supports. The SST tries to be there, but they are so thinly stretched...What safety net do we have?”

Another interviewee reiterated what had been regularly heard from others with regard to crisis services, ‘Oh I need a crisis system. I need a crisis system today. I need a crisis respite. I got people who I take to 15 different places before I can get them admitted for mental health services. I need that today.’”

Stakeholders estimated that 60-65% of JDC residents had behavioral concerns in addition to their disabilities. Others indicated that challenging behaviors presented problems when transitioning individuals into group homes due to a lack of resources available to support people with such behavior needs. One stakeholder said, “...I think the biggest issue is a lack of placements for individuals that have more challenging behaviors.” The lack of resources left some providers feeling unable to offer enough services for consumers. Providers that did not have a behavior support specialist on staff often sought hospital placements for consumers whose behaviors could not be

managed by staff. One stakeholder commented, “I was surprised at how willing providers were to take behaviorally complex consumers, consumers who would have been dangerous in terms of their behavior. They were really willing to work with us on that.”

Stakeholders expressed the need for greater access to health services, such as dental care, physical therapy, and other medical services, which in part was due to the Saving Medicaid and Resources Together (SMART) Act that reduced dental and physical therapy services for people on Medicaid in Illinois effective July 2012.

“If there could be some provision in individual service plan. If you set aside some money for dental on top of what Medicaid provides, we might be able to encourage some dentists.

Another issue related to health care access is the need for health care professionals knowledgeable about I/DD and willing to serve them. One person said, “Trying to find dental care for people (with IDD) is almost impossible. And physicians that are familiar with our population ...” Not only are dentists and physicians unfamiliar with serving people with IDD, Medicaid reimbursement rates are considered a barrier.

Due to these types of perceived gaps in the community service system, one respondent stressed one reason for maintaining an SODC, “[If we] can free up like ten beds under census... They will at least have a place to come to see a dentist or a doctor or something... so that [it] is going to serve as a support and that's where the experts are. You bring them there until you get services created in the community.”

Another person stated, “... there is a systemic failure to do prevention, implementation of the recommendations, early intervention, resolution, support to the individual or wrap around or enhance those services and support and it's like the only time we can [get] anyone's attention is when it is like blowing up and even then there is no good answers.”

QUALITY ASSURANCE

Although the closure process was stressful and overwhelming for stakeholders they felt as though their efforts were worth helping individuals from JDC achieve a higher quality of life. As one person said,

“I mean did we go through a lot. Yes. But was it worth it? Hell yes. Every smile. I mean yes it's well worth it. And you know you want to knock on something, but everybody is doing great. That's what we do. That is your reward is seeing that you really, truly helped those individuals.”

Positive Client Experience Post-Transition

Overall the individuals who had transitioned into group homes were described as being happier and more verbal. They were able to choose the types of food they wanted to eat/drink, use the restroom when they wanted, or go for walks in the neighborhood. One stakeholder commented,

“Meeting them in an institution and then meeting them in their home and seeing how different they were. Not just that they [are] happier, but that this guy said not a single word in the institution and now he is asking you for the types of foods that he wants. Now he is getting to use the restroom when he wants to use the restroom. He can pick his own food and drink. He doesn't have to ask someone to get it for him. I mean it was amazing getting to see those things”.

Individuals who transitioned into group homes were described as experiencing a higher quality of life and thriving in their new homes; they were adjusting well to community living, socializing with housemates and staff, as well as participating in community activities. One stakeholder commented,

“I mean, when he first moved to the house, there was no social interaction at all. It was ‘I'm in my own space. I am going to stay away from everyone else. Don't come near me. Don't talk to me’ type of thing. Now

he is going to everybody, wanting to interact with people. He is very active in the house. Sits with the other housemates to watch TV.”

“Even the guardian has said just looking at him, he looks like he is more healthy. Like he is eating better. His color is so much better. He just looks like he is younger a little bit even. She said, “I've seen this huge transition.”

Providers noted that former JDC residents have embraced the independence in the group homes, but also find comfort knowing there are staff they can go to if they require help. One person said, “...I think that is definitely ... one reason why we have gotten such a positive outlook from them was because they see the independence that we're giving them, but yet they know that if we do have an issue, that we're right there. And I think that's a big thing for them.”

PHASE III: FORMER RESIDENT INTERVIEWS

Phase III of the evaluation involved face to face interviews with individuals who moved out of JDC as a result of its closure for the purpose of gathering qualitative data. Among the Family/Guardian Survey materials sent to guardians was a consent form to interview the individual who moved out of JDC (see Appendix C). In addition to seeking permission to interview, guardians were asked to indicate contact information for personnel who would be able to assist with scheduling an interview. Designated personnel were then contacted by a member of the research team to schedule a date/time and location convenient to the interviewee. After guardian consent was obtained, assent was obtained from the individual who moved out of JDC. All of the individuals for whom consent was obtained also provided assent to participate. All interviews were conducted in person.

Interviews were conducted using an interview guide (which can be found in Appendix D) with questions along five core domains:

- The decision to close JDC;
- Transition plan;

- The move;
- Relationships; and,
- Quality of life.

The research team worked with the Assistive Technology Unit at UIC to develop graphic aides to assist in interviewing former residents. Several of the individuals for whom consent was received were non-verbal and do not use communication devices and were therefore not interviewed.

A member of the research team interviewed 15 individuals; fourteen males and one female. Interviews were conducted in the setting of the interviewee's choice, which was typically their developmental training program or their current residence. Of the 15 individual participants, three were living in an SODC (2 at Shapiro and 1 at Ludeman) at the time of interview and twelve were living in a community placement. Upon completion of the interview, each participant was given \$20 in cash as compensation for their time.

Interviews were conducted utilizing an interview guide which listed the questions to be asked during the course of the interviews. An interview guide offers a systematic approach to interviewing a number of different individuals along basic lines of inquiry (Patton, 2002). In addition, it allows for a conversational tone between the interviewer and the participant in which the asking of probing questions comes naturally. Despite the use of graphic aids, two individuals did not answer interview questions and therefore their responses were not included in the final analysis.

Interviews were recorded (with permission) and later transcribed for analysis. Other than general characteristics that can be determined visually (e.g., gender), demographic information was not collected. Data was initially analyzed for general content themes by listening to the recordings, reading transcripts and grouping similar responses and summarizing. Responses were coded along the five core domains: 1) the decision to close JDC; 2) transition plan; 3) the move; 4) relationships; and 5) quality of life. Such triangulation of qualitative data strengthens qualitative research thus improving the validity and consistency of conclusions (Patton, 2002).

PRE-TRANSITION THEMES

Reaction to Closure

Former JDC residents shared how they learned about the closure. Some found out from the newspapers, the radio or from the television news. Some saw Governor Pat Quinn speak about the facility shutting down on television. One person shared, “I heard it on the Fox 2 News and the News 20...I heard about it Pat Quinn was talking about closing it down...they said it broke because they had to close it down because it was broke.” The individual went on to explain, “We found out when Jim Watson and Sam McCain came down and Mayor Andy, or whatever his name is, from Jacksonville came in front of our building and was getting interviewed by the news crew and all that stuff and that’s how we found out.” Other residents found out from their peers and staff that JDC was closing. One person said, “I just talked to a kid... He used to live there...He told me Jacksonville was closing.” Some participants indicated that they were not aware that JDC had closed down, “I moved into my brother’s house...I didn’t know Jacksonville closed. How come they close[d]?”

“I heard it on the Fox 2 News and the News 20...I heard about it. Pat Quinn was talking about closing it down...they said it broke because they had to close it down because it was broke.” ~ former JDC resident

Former JDC residents stated that they were happy that JDC was closing; however, they indicated that initially they felt upset because they would miss their friends and staff. One person stated, “I was glad that they were closing it because I could not wait for them to close it!” Another stated, “I am glad I am out of JDC!” Other individuals said they felt angry due to not being informed that the facility would be shutting down. One person said, “I was angry...because I heard Jacksonville was closing. I never knew it was closing.” Others spoke about their fear not knowing where they were going to live after JDC closed. One person said,

“It was hard for everybody and not everybody got to do what they wanted. Some of them wanted to go home with their parents. Some of them wanted to be in a group home. But some of them got moved to Developmental Centers. It was hard for everybody, including me. I didn’t like it but it was just something that I had to do.”

TRANSITION THEMES

Pre-Transition Visits

Some individuals indicated they were given an opportunity to visit their new home, while others indicated they had not. Those who did a pre-transition visit indicated that they typically saw the physical home, however, did not get an opportunity to meet staff or other residents. They described that visits were typically brief and did not involve an overnight stay. Some individuals stated that they had not visited other homes to compare and determine which one they liked best, so they could choose between options.

Choosing a Home

Former JDC residents commonly spoke about their guardian, specifically their mothers, making the decision about where they were going to live.

“Yes, [staff] talked to me about my moving options and I told them I would rather go, but ...I mean I was told I was going to [agency] wherever [agency] is at. It’s either a facility or a group home. But then on top of that and then I got [crossed] off the list because it was somewhere where my mom doesn’t want me to go, somewhere out north. So she

“I got [crossed] off the list because it was somewhere where my mom doesn’t want me to go, somewhere out north. So she doesn’t want me anywhere up north where Chicago is...Other than that, this is the only option.”

~ former JDC resident

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Additionally, former residents spoke about how their desires to move closer to their family were not met. For example one individual stated "Because I told them where I wanted to move. I wanted to move close by my mom because this ain't close by my mom because this is in Chicago and my mom is in [a rural city]."

"...I told them where I wanted to move. I wanted to move close by my mom..." ~ former JDC resident

While some individuals spoke with their staff and guardians, others expressed that they did not feel as though their voices were being heard related to where they wanted to move. One individual stated, that during a meeting they felt that their needs were not addressed and were overshadowed by what other people thought was best,

"I didn't make the decision. I had an interview. I had a whole bunch of people come see me. First people asked me to move somewhere else and some people wanted me to move close by to Jacksonville in another place in Jacksonville, another place in a house close by Jacksonville when I can still work at [employer]. But then somebody wanted me to move close by somewhere else and somewhere else and then somebody wanted me to move down close by Chicago in a house. But I didn't want to move here."

One individual expressed his desire to live in an apartment, however, due to a criminal record he was not eligible and moved into a group home instead. He shared,

"I had talked to John from DHS in Springfield and I talked about moving in an apartment. But they [said] something about since I was arrested or whatever, when I was filling out an application one day to see if I could move or whatever before JDC shut down because I had an option

between an apartment and group homes. When I was talked to by several people in the CILA's and then I filled out an application for an apartment or whatever. Apartments won't take you because if you have been convicted of assault or whatever or any conviction or whatever they won't take you. I just read that little fine print whatever on there so it really ticked me off. That happened so long ago, I don't know why it would matter, but my charges were dropped."

Communication

Individuals shared that they relied on JDC staff, siblings and mothers to answer questions related to the closure process and the move. One individual stated, "Sometimes I talk to... [JDC] staff...They talked about [the closure]. Said that we need to pack our stuff and get ready ... that Jacksonville was getting ready to close and get stuff that we need take..." Some individuals, however, did not feel as though they were kept well informed by JDC staff, their guardians, or family members about the moving process and expressed this to be a scary time for them as they did not know what to expect next in the process.

PCP Meetings

Individuals were divided with regard to their experiences with PCP meetings. For example, some individuals stated that they did not have a meeting to discuss plans to move to a new home, their needs, or desires. This may have been due to their guardian not wanting them to participate in the PCP process. Some seemed confused about the terminology and/or the content of the question. Recollection of the meetings may have been limited due to the amount of time that passed from when the individual left JDC and when the interview was conducted (which was in excess of one year).

Some individuals discussed how during the meetings they expressed their needs and interests. One individual shared, "[I] told them that I liked working on cars and that I wanted to help like, build houses and stuff and restaurants and stuff like that and do." However, although individuals were present during their ISP meetings, they indicated that they did not feel as though the meetings were productive in being able to address their needs.

Interviewer: What sort of things would you like in a new house?

Individual: I tried to explain that at the meeting, but they didn't hear anything I said.

Interviewer: Really? What sort of things did you want?

Individual: I could get Blu-ray. I tell I want a Blu-ray.

Another individual shared their experience of participating in their PCP meetings where they met with many stakeholders with competing interests:

“People coming from internal affairs or whatever it is called -Equip for Equality is what it's called. People from there were all coming and then [staff member]... from Equip for Equality and then a couple people from DHS from Springfield came and was interviewing people to go to CILAs and stuff and [agency] and a couple other CILA's and stuff and [agency] in Jacksonville. But none of them were able to meet my needs. And then they tried Springfield, Illinois and there was nothing down there. It was all youth homes or whatever, younger people not my age to be in whatever. Because they have homes for younger people and then they got one for adults.”

THE MOVE

Individuals not only had to contend with a move from JDC, some had to move several times between units on JDC's campus prior to their official move. One individual described,

“Well, when I moved to Jacksonville, they moved me back and forth, back and forth from units I am at. I was on the southwest and they moved me to the east side and then I was from the east side to the northwest and then I moved back to the east side when they were doing cleaning and stuff you know, tearing up the floors and

everything. Then we all had to be moved to the east side. They shut the whole floor down. It was kind of complicated.”

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~ former JDC resident

Fear was another factor that impacted the move from JDC. An individual described the moving process as a “monster” while another stated,

“...it was kind of complicated and stressful, nervous. But other than that, I told myself I could make it and not to be afraid about it. I don’t like change. I don’t like moving. I like being stuck where I am at because change is the only thing. It’s an OCD thing.”

Such apprehension and fear may have been a result of them not feeling as though they were kept informed about the moving process as indicated previously. Individuals discussed feeling as though they did not receive enough notice about their moving date and felt rushed, nervous and scared about the move. One individual said, “My name was on the list and it was on for that certain day and I had to leave that morning. No, I didn’t have enough time.” Individuals typically described moving day as packing up their belonging in boxes or bags and loading them onto a truck. Individuals spoke about bringing their belongings such as stereos, books, DVDs, books and

clothes, but had to leave larger items behind. For example, one individual stated, “We had a conference meeting and told me what I could bring and what I couldn’t bring and all that other stuff. I was surprised I couldn’t bring my own refrigerator or my bed, but oh well. Then I was told we could bring our own bed, but then it wasn’t the right size for the bed frame so it wouldn’t make no difference.”


POST-TRANSITION THEMES

Satisfaction with New Home

Many individuals explained that they were happy living in their new residences which may have stemmed from having choice in activities to do as well having new neighbors. One individual stated, “I like it here. It’s so fun. I could do more activities and you know do shopping and things like that.” Former JDC residents indicated activities they participate in the community, such as “going to movies,” “swimming and bowling,” “going out to eat, going to dances,” “outings,” “...the park,” “Six Flags,” and “Play kickball, play basketball and do sports.” Some individuals compared their new residence with their old residence at JDC saying that, “I am glad I am out of JDC,” and “I like this place better [than JDC].” Individuals conveyed some of the differences between living at JDC and their new residence. Some of these differences include “[Shopping] is more better convenience to me,” “I got cable [TV] on it,” and “I have my freedom.”

Some individuals indicated that they would like to do additional community outings, such as fishing. Individuals who lived close to the metropolitan areas like St. Louis and Chicago said that they were able to go to sports games. One person said, “I like Chicago. I like going to Chicago, going to Bulls games. I went to basketball games. I went to the college basketball game with my staff.”

Individuals also indicated increased involvement in activities they enjoy. Such



“I like it here. It’s so fun. I could do more activities and you know do shopping and things like that.”

~ former JDC resident

activities included: gardening, cooking, art, movies, and music. Comments included, “Work in my garden right there,” “I learned how to cook,” “decorating and coloring and painting,” “watch movies,” “listen to music,” and “sit on my porch.”

Individuals indicated that they were often in charge of what types of community activities in they participated, although, one resident indicated this was not always the case stating, “Sometimes. Sometimes not.” Another expressed, “Sometimes I do [choose] and sometimes I don’t.” Others mentioned particular things about their new residence such their new room, and the food. “I like it here and I really like my room and everything.”

Not everyone was satisfied. A few people said that they would like to move into their own apartment. One CILA resident shared,

Former Resident: I can’t stand it here, but it get off in March. I am hoping to take my guardian to court to see if I can [be] my own guardian then if the judge let me I can [move out]. But I would have to go out and look for you know like an apartment or something.

Interviewer: Do you feel happy with your life right now?

Former Resident: Well, no, not until I move out of here and like out all on my own. Then I will be happy and I will be glad.

Individuals also indicated increased involvement in activities they enjoy. Such activities included: gardening, cooking, art, movies, and music. Comments included, “Work in my garden right there,” “I learned how to cook,” “decorating and coloring and painting,” “watch movies,” “listen to music,” and “sit on my porch.”

Another CILA resident explained the desire to move back into the family home:

Interviewer: Do you want to keep living here?

Former Resident: No.

Interviewer: Where do you want to move?

Former Resident: I want to move back home.

Interviewer: Back with your parents?

Former Resident: Yes, with my mom and dad.

Interviewer: Maybe another house will open up near your parents.

Former Resident: I know. I am going to be patient. My life has been better since I moved in.

“Since I have been in every facility that I have been in, there have only been like eight people, but 16 people is kind of clustered.” ~ former JDC resident

One resident who relocated to another SODC explained their frustrations in living with a large number of people,

Interviewer: You have more people in this unit?

Former Resident: Since I have been in every facility that I have been in, there have only been like eight people, but 16 people is kind of clustered.

Interviewer: So what kind of limitations do you feel with so many people here?

Former Resident: Sometimes if I am with a floor with 16 like and my mama and I talked like I feed off of other peoples' behaviors sometimes.

There was a range of answers when asked how long each person planned on staying at their new residence. "Yes I'll stay here forever. Until I get my own apartment again. I used to live in an apartment..." Other responses included, "Forever," "I don't know," and "For a while." Another individual, who moved into an SODC, expressed serious interests in pursuing another residence explained their moving situation,

"I told my mom I wanted to get out of here by at least 2019 or 20, but she thinks I need to stay a little longer ... Get settled in before I move out and do other things. I keep telling her, 'Well I am ready for an apartment,' but she doesn't think I am ready for an apartment because she doesn't think I can do it all by myself on my own in an apartment and stuff"

"I told my mom I wanted to get out of [the SODC] by at least 2019 or 20, but she thinks I need to stay a little longer..." ~ former JDC resident

Former residents were asked if they felt safe in their new community and new residence. Most responded, "Yes." Many individuals explained that they would tell a staff person if they felt unsafe. One person said, "Yes. I tell [staff name] I don't feel safe. If I get upset I talk to him." Others said that they would call the police or 911 if they didn't feel safe. Additionally, they were asked if they believed that their personal property was safe in which most responded "Yes."

Day Program/Work

Most individuals interviewed were engaged in some type of day program or work. In fact, a variety of different jobs people had were mentioned. One person said, "I do a lot of work with brick," while another shared, "Like I go to work in a kitchen. I work

Mondays and Tuesdays in the kitchen. It's good. I work hard and make some money." One person mentioned that they were going to be interviewing for a job at a "coffee shop."

Some former residents indicated that they would like to explore competitive employment to increase earning potential. One such person shared,

Interviewer: How do you feel about your day program you go to?

Former Resident: I don't like it there. I hate it there.

Interviewer: Why?

Former Resident: I don't like there because I don't like it. I don't stay in the building there. I don't like it.

Interviewer: Is it the stuff you do?

Former Resident: I want to do this (rubbed together thumb, fore- and middle fingers indicating money).

Interviewer: You want to make some money.

There was a mix of satisfaction and dissatisfaction with day programs and jobs expressed. One person said, "I like going to workshop. I like going to work." A few people indicated they were able to continue with their same job or day program they had while at JDC. Many people indicated that they got to go on "outings" with their day program. Others were engaged in classes, either as a part of, or outside of, their day programs, such as "art" and "wood shop."

Relationships

Social interaction was an important factor for individuals who moved from JDC. When asked, most individuals said "Yes," that they felt that staff were respectful to them

and explained things in an understandable manner. One CILA resident elaborated, “Yes. If I need to talk to someone I talk to them. And I like them. I like staff here... They did treat me with respect.” Not all interviewees indicated satisfaction with staff. One CILA resident said, “I don’t like the staff here. They treat me.... Like sometimes, like, I don’t get my way... Like, if I do something, I get in trouble.” Most of the respondents indicated that they liked their housemates. Another CILA resident expressed being dissatisfied with some staff, “Some of staff can be critical. Not doing what they should. We got some new ones. I like them. [Staff] is new and I like her.”

One person expressed their feelings when asked if they like their housemates, “Sometimes. But some people, [housemate], get on my nerves. Hard with the screaming and I don’t like nobody.”

Many individuals indicated that they had family living close by their new residence. Some stated that they had family living, “A couple blocks from me,” or “About probably 30, 35 or 40 minutes.” Others indicated that they did not. For example one person said, “My dad and my mom is in [city]. I don’t see my mom and dad,” while another indicated their family was three hours away, “Yes. It’s three hours,” or in another state, “Mother moved to [another state].”

One person said that “the neighbors” were the best part about living in their new area. Another person, however, said that they wished they had some neighbors at their new home.

As some residents lived at JDC for many years, they developed strong relationships with staff who worked there. Several individuals interviewed expressed missing friends and previous staff at JDC. One person said, “It’s kind of hard to be away from my old [JDC] staff.” One person described her relationship with a JDC staff, “I am attached to [JDC staff’s name] because he never had girls. He has two sons and another one too. He never had girls, but he adopted me as a stepdaughter to him.”

“It’s kind of hard to be away from my old [JDC] staff.”

~ former JDC resident

Many individuals interviewed explained that they were able to, or attempted to, remain in contact with their former staff and in general, most residents expressed some level of continued communication. One such individual provided details on their communication with a previous JDC staff,

Interviewer: So you do call your friends from Jacksonville?

Resident: Yes. One of my staff called me yesterday at Jacksonville.

Interviewer: So they try and keep in touch with you?

Resident: Yes, some come and call me on the phone.

A large number of residents indicated that they have maintained contact with old friends from JDC. In fact, some individuals were able to transition to their new home or new community with friends. As one CILA resident shared,

Interviewer: So all your other friends from Jacksonville, do you get to see them very often?

Resident: Yes.

Interviewer: Where do you see them?

Resident: Here.

Interviewer: Are some of them they moved in here too?

Resident: Yes.

When asked what they missed about living at JDC, one individual elaborated, "Losing my friends. Want my friends." A few individuals indicated that they were not engaging in contact with old friends or staff from JDC. One individual responded, "I can't because I don't have no friends." Some indicated that their friends lived "far away."

Others indicated they do not have family or friends living near their new residence. One individual, who had moved near Chicago, explained their situation:

Interviewer: Are there a lot of friends from Jacksonville that live around here?

Former Resident: No

Interviewer: So, do you miss Jacksonville while you are here?

Former Resident: Yes, very much. As much as I talk to my girlfriend that I want to come back. It's just driving me nuts. Everybody misses me down there. But they all wanted to come back.

In fact, many former residents who were interviewed said that they had engaged in some sort of romantic relationships while they were living at JDC. One resident expressed, "My favorite thing is going on a date and go out and eat." Some of the residents who are involved in romantic relationships mentioned that they are still able to see their girlfriend/boyfriend. One CILA resident said,

Former Resident: My girlfriend came up here to see me one time.

Interviewer: So you don't get to see each other often?

Former Resident: No.

Interviewer: Would you like to see her more often?

Former Resident: Yes.

One SODC resident explains his correspondence with his long-distance girlfriend,

Interviewer: Who do you write letters to?

Former Resident: My girlfriend, my sister and my brother, just pretty much all my friends.

Interviewer: Does your girlfriend live in Jacksonville area still?

Former Resident: Yes, about four hours from here. She wants me to come back down there...

Many former JDC residents indicated that they have made some new friends at their new residence. Many of them named the people with whom they had become friends, including staff and individuals they have met during their day activities. One person responded, “Yes, I got friends in my class and stuff.” A couple of individuals, however, indicated that they have not made any new friends at their new residence, saying “No, not yet” and “No.”

Dating was an important topic to interviewees. One individual explains,

Interviewer: Are you interested in like making new friends while you are living here?

Resident: Yes. Plus meet a new girlfriend... I want a girlfriend.

Individuals spoke about keeping in touch with their family and friends through letters and phone calls. Some individuals, however, expressed frustration with writing letters and not getting any response back, or not even being sure if they had the correct mailing address of their friends. Additionally, individuals discussed their frustrations with not being able to use their house phone as desired; some CILA residents stated they have designated phone days and times when they were permitted to use the phone.

Privacy

When individuals were asked if they had enough privacy at their new home, many of them said “Yes.” “I got my own privacy,” a CILA resident said as he pointed at the bathroom. Other CILA residents said, “I get my privacy at night time” and “occasionally”.

One person who transitioned to another SODC, explained the rules on using the bedroom for privacy,

Interviewer: Can you go into your room when you feel you need privacy?

Former Resident: Only if I have staff permission to go in there. We have to ask before we can go in there to let them know where we are at all times. Whether we have mobility or we don't have mobility.

Another CILA resident explained,

Interviewer: Do you have any restrictions on privacy or you can just go to your room whenever you want to?

Former Resident: I can go in my room to do anything.

Another CILA resident, however, stated, "No. I don't have privacy. I never get privacy. When I go to my room all the time, people knock on my door and want me to do [expletive]. I can't watch my own TV. I can't do nothing."

Finances

Individuals shared information related to personal finances such as going to the bank to deposit their checks, how they are working towards budgeting their money, and that they commonly spend their money on food, CDs, DVDs, batteries, clothing and going to the movies. One individual shared that he was putting his money in the bank because he is saving his money to purchase dentures, and other individuals talked about the desire to obtain a credit card. Individuals also spoke about their feelings of not having enough money to meet their needs. For example, one individual said, "I need more [money]...I need more than \$15 dollars a week."

The amount of money a person has often determines how often and where they participate in community activities. One person shared, "Wal-Mart, out to eat outings, shopping, clothing shopping. It depends on how much money we got in our accounts depends on where we go."

Access to Technology

Individuals talked about enjoying having access to a computer within their home but were limited in what they were able to access. For example, an individual stated

they liked to “[I] listen to music, play games on the internet. They only have certain things on the internet you can go on and play like, stuff like Solitaire. They got like some kind of education games and stuff and all that other stuff.” Another individual explained his limited computer use stating, “I used computer like, you play games or anything on it. You type your name on it and your address, but that’s all I did.”

Individuals typically said that they used the internet to research their favorite music stars, such as Elvis Presley and Michael Jackson, or to search cooking recipes. For example, one individual stated “You can look stuff up like, if you want to look what kind of food you want. Because I look for like, recipes and stuff in it. One time I looked for lasagna and spaghetti and stuff like that.” Individuals expressed interest in acquiring laptops, iPods, and cell phones.

Alternatively, other individuals talked about not having access to computers within their home, but wished that they did. Some individuals utilized computers they have at their workplace, but find it difficult to access the computer because others were using them. Other individuals looked forward to going to their parent’s home so that that they could use the computer there. They spoke about the value of getting a Facebook account so that they could keep in touch with their friends and family members. One individual stated “I would like to get on Facebook,” however did not have an account, know how to use it, or believed they could not get an account because they believed that they had to pay for it.

Aspirations

Individuals frequently spoke about their desire to become more independent; specifically to find a job at a local store or coffee shop. One individual provided examples of desired employment opportunities, “like, getting another community job part time, work at Dollar Tree or the mall or something like McDonald’s or something like that.” Other individuals discussed their desire to move into an apartment and live alone. One person said “Well, I [would] like being in an apartment house...I just feel like I have my own living on my own self in an apartment house and that’s the way I feel.” One individual discussed how he plans to get married and eventually move out of his current home. He stated,

“Because I ain’t going to be here too much because I am moving. I am moving somewhere else because I am setting a date - me and my girlfriend are setting a date because I am going to get married

Individuals were aware of plans in place to assist them in working towards greater independence. They gave examples, such as following house rules, taking their medication regularly, learning to budget their money and making good choices. However, some individuals talked about the difficulty to be more independent because they feel that staff limit their community access. Additionally, it was shared that if an individual has displayed maladaptive behaviors staff will not allow that individual to go out into the community as a consequence. One SODC resident shared,

“The rules are different. The difference between here and there, I mean staff there they gave you a lot more leeway than they do here. But less rules there than they do here. Their mobility [going out into the community] over there, they let you go off grounds.”

Post-Transition Follow-Up

One individual explained that a couple of DHS staff came to follow-up with them after their transition to their new residence,

“[Personnel] from DHS. There was somebody else. I’m not for sure who it was. [Personnel] from DHS. And that has been the only two people. They come and check on the people since they have been here for a little bit. Like they first come out here and check on them and see how they are doing and everything else. But other than that, that’s the only two people.”

Others said “No,” that they were not aware of any follow-up visits.

PHASE IV:

FAMILY/GUARDIAN FOLLOW UP SURVEY

Methods

Phase IV of the JDC closure evaluation used data obtained through a paper-based survey sent to family members/guardians of people who had moved out of JDC. The survey included 26 multiple choice questions on:

- Demographics of family members/guardians (respondents) (age, gender, race/ethnicity, education level);
- Demographics of the former JDC resident (age, gender, race/ethnicity, education level);
- Respondents' satisfaction with the former JDC resident's new placement and services; and
- Changes in the former JDC resident that the respondent has noticed.

Survey materials (cover letter, survey, and a postage paid return envelope) were prepared by the research team at IDHD and mailed by the Illinois Division of Developmental Disabilities to all 180 guardians to ensure respondent confidentiality. All surveys received by the research team were anonymous unless the respondent indicated his/her name or the name of the former JDC resident on the survey; however, this information was not requested. The survey materials were distributed twice (May and August 2014), and a total of 68 surveys were returned from the 180 family members/guardians (37.7% response rate, which is consistent with similar paper-based studies of a Medicaid population that used mailed surveys (Gibson, Koepsell, Diehr, & Hale, 1999; U.S. Agency for Healthcare Research and Quality, 2001)). Upon receipt, the survey data were entered into Statistical Package for the Social Sciences (SPSS) version 22.0 for analysis.

Results

Demographics

Approximately 84% (n=57) of survey respondents indicated they were family members (parents, siblings, or grandparents), while the remaining 16% were state guardians. Table 10 presents the respondents' relationship to the former JDC resident.

Table 80: Respondent Relationship to the Former JDC Resident (n=68)

Relationship	n	%
Parent	40	58.8
Sibling	16	23.5
Public Guardian	11	16.2
Other (grandparent)	1	1.5

The mean respondent age was 69.7 years old (SD=11.6 years), and the majority of respondents (64.6%) were older than 65 years. Over two-thirds of respondents were Female (73.5%). The vast majority of respondents were White (82.4%), followed by Black (7.4%), and Other (4.4%). Four respondents (5.9%) did not answer the question about their race/ethnicity. Nearly half (47%) of the respondents graduated from college, while approximately 25% went to some college (23.5%) or had a high school education or less (23.6%). Four respondents (5.9%) did not report their education level. Table 11 (next page) presents additional respondent demographics.

Table 11: Survey Respondent Demographics (n=68)

Demographic	n	%
Age		
65 or older	42	60.2
Less than 65	23	35.4
No response	3	4.4
Gender		
Female	50	73.5
Male	18	26.5
Race/Ethnicity		
White	56	82.4
Black	5	7.4
Other	3	4.4
No response	4	5.9
Education		
College graduate or more	32	47.0
Some college	16	23.5
High school or less	16	23.6
No response	4	5.9

Respondents were also asked to provide demographic details about the former JDC residents (Table 12, next page). The average age of the former JDC residents was 49.0 years (SD=12.5), ranging from 21 to 78 years. The majority of former JDC residents were male (77.9%) and White (77.9%). Those surveys represented an even distribution of former JDC residents in terms of how long they had lived at JDC: 37% have lived there for less than 10 years; 29% had lived there between 11 and 20 years; and 25% had lived there for 21 years or more. Nine percent of survey respondents did not respond.

Table 12 also provides the demographics from the overall population of former JDC residents (using JDC census data provided by the Division of Developmental Disabilities). This data showed that just over 59% of all the former JDC residents were White and almost 40% were Black. These were statistically significant differences, and indicated that the survey significantly overrepresented White former JDC residents and underrepresented those who were Black.

Table 12: Former JDC Resident Demographics

Demographic	Survey responses (n=68)		Overall Former JDC Residents (n=414)	
	n	%	n	%
Age				
50 or older	33	48.5	211	51.0
Less than 50	35	51.5	203	49.0
Gender				
Male	53	77.9	303	73.2
Female	15	22.1	109	26.3
Missing	0	0	2	0.5
Race				
White*	53	77.9	143	34.5
Black*	8	11.8	96	23.2
Other	3	4.4	2	0.4
Missing	4	5.9	173	41.8
Years at JDC				
10 or less	25	36.8	207	50.0
11 to 20	20	29.4	92	22.2
21 or more	17	25.1	114	27.5
No response	6	8.7	1	0.2

* Significantly different from anyone who transitioned from JDC

Former JDC Residents' New Setting

The survey respondents were asked what kind of setting the former JDC resident family member moved to (Table 13, next page). The majority of respondents (57.4%) indicated that the former JDC resident transitioned to a Community Integrated Living Arrangement (CILA), followed by another SODC (20.6%), or an ICF/DD (17.6%); one former JDC resident family moved to an "Other" setting (1.5%) and two respondents did not answer this question (2.9%).

Table 13: Former JDC Residents' New Setting (n=68)

Setting	n	%
CILA	39	57.4
Another SODC	14	20.6
ICF/DD	12	17.6
Other	1	1.5
No response	2	2.9

Satisfaction with New Home

The survey respondents (n=68) were asked how satisfied they were with the former JDC resident's current living situation. The majority (55.9%) were "Very satisfied" with nearly a third (30.9%) feeling "Somewhat satisfied." Only 11.8% of respondents felt either somewhat dissatisfied or very dissatisfied with the former JDC resident's current living situation. One respondent (1.5%) did not answer this question.

Figure 20 (next page) illustrates the survey respondents' satisfaction with the former JDC resident's current living situation for respondents who were family members of the former JDC resident (n=57). The majority of members (59.6%) were very satisfied with their relative's current living situation and nearly a third (28.1%) were somewhat satisfied. Only 11.3% were either somewhat dissatisfied or very dissatisfied.

Figure 20: Family Members' Satisfaction with the Former JDC Resident's Current Living Situation (n=57)

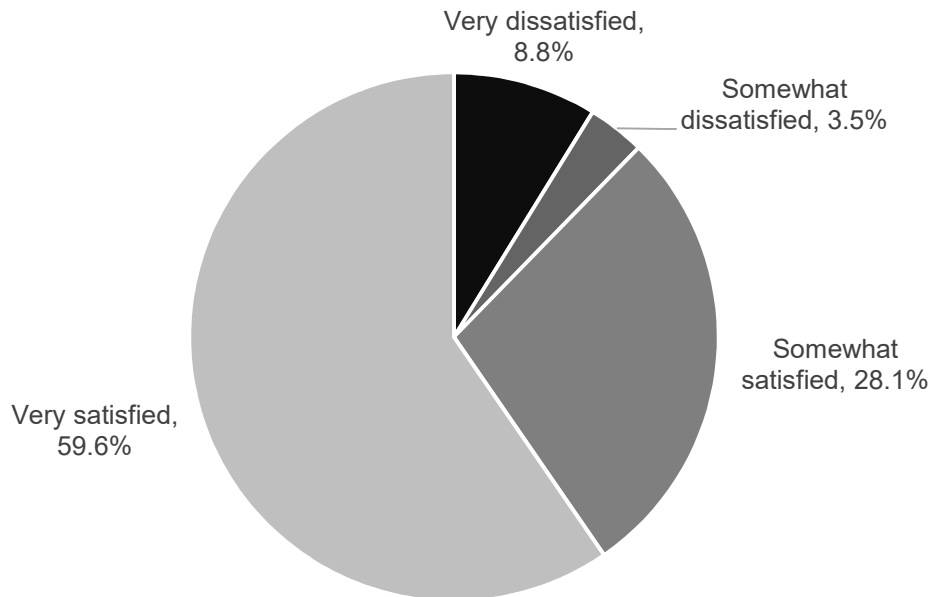
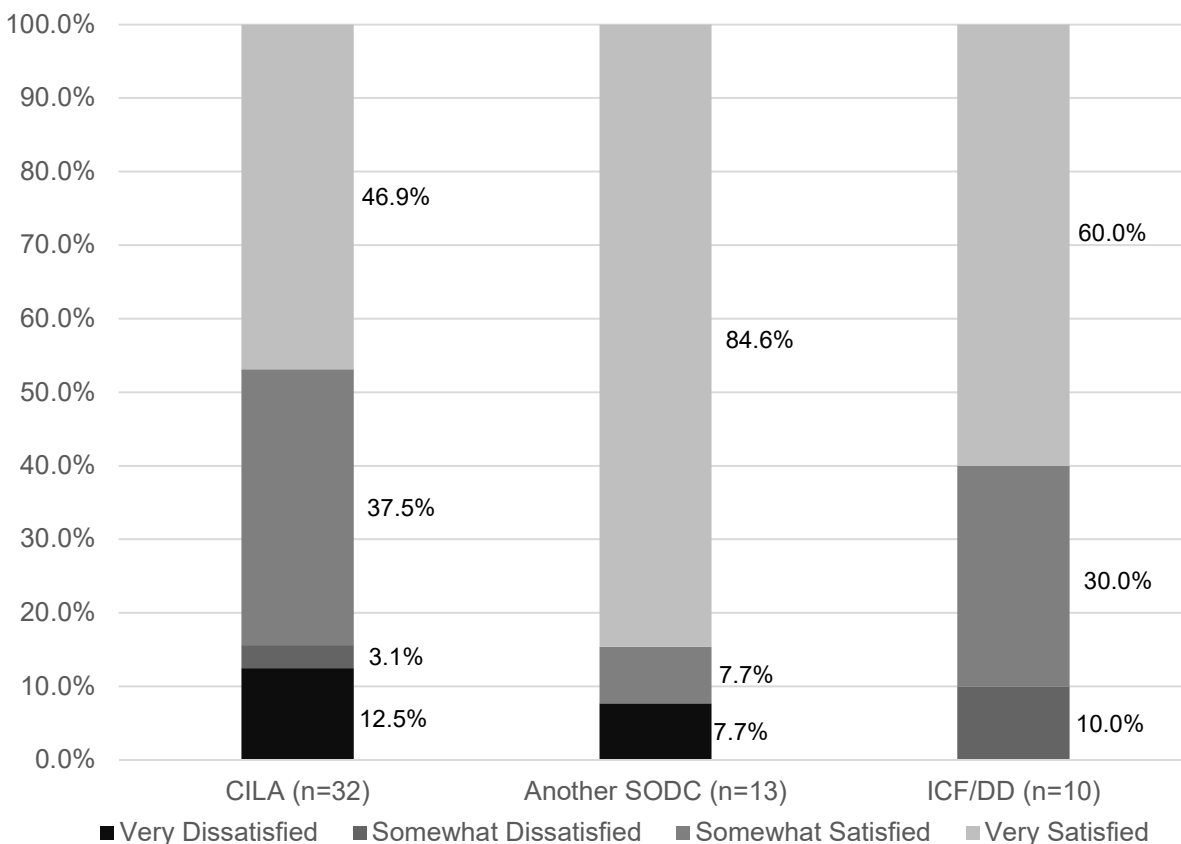


Figure 21 (next page) further expands on Figure 1 by separating family members' satisfaction with the former JDC resident's current living situation according to where the former JDC resident moved. If the former JDC resident transitioned to a CILA (n=32), the majority of their family members (84.4%) were either somewhat or very satisfied with the former JDC resident's current living situation. Family members of 12 of the 13 former JDC residents who transitioned to another SODC (92.3%) were either somewhat or very satisfied with the former JDC resident's current living situation. Finally, family members of 9 of the 10 former JDC residents who transitioned to an ICF/DD (90.0%) were either somewhat or very satisfied with the former JDC resident's current living situation.

Figure 21: Respondent's, who were Family Members, Satisfaction with Relative's Current Living Situation by Setting



Family members who responded to the survey (n=68) were asked how much they agreed with the following statements: (1) "I believe that [the former JDC resident] receives adequate supervision at his/her new home," (2) "Needed services are available in [the former JDC resident's] new home," (3) "S/he likes staff that work with him/her at the new placement," and (4) "S/he gets along with his/her new housemates." The majority of respondents either somewhat agreed or strongly agreed with the statement that the former JDC resident received adequate supervision at their new home (93.0%); needed services were available at the former JDC resident's new home (85.9%); the former JDC resident likes the staff at their new placement (65.5%), or the former JDC resident gets along with their housemates at their new placement (65.5%) (Table 14, next page).

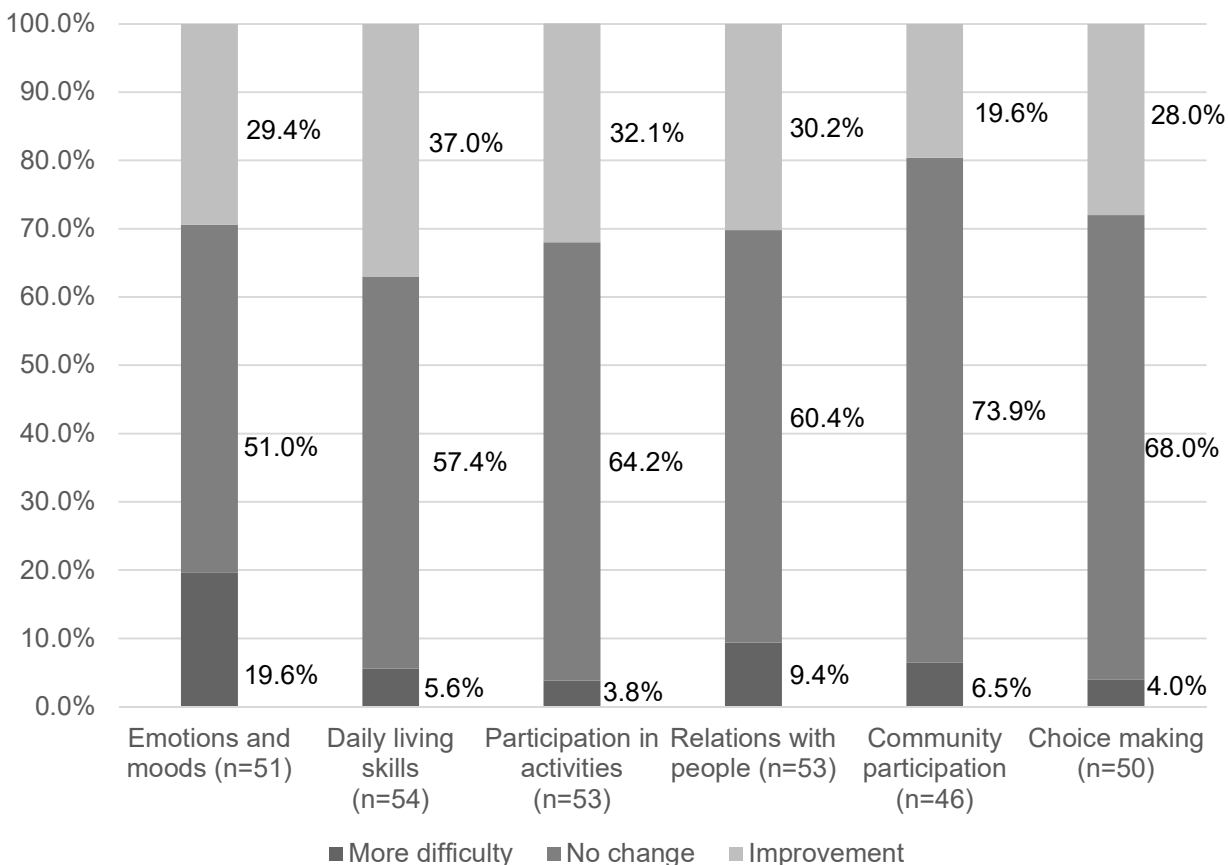
Table 14: Respondents' Assessment of the Former JDC Resident's New Living Arrangement (n=68)

Statement	n	%
"I believe that [the former JDC resident] receives adequate supervision at his/her new home"		
Agree	63	92.7
Disagree	4	5.8
Missing	1	1.5
"Needed services are available in [the former JDC resident's] new home"		
Agree	58	85.3
Disagree	8	11.8
Missing	2	2.9
"S/he likes staff that work with him/her at the new placement"		
Agree	51	65.0
Disagree	2	2.9
Missing	15	22.1
"S/he gets along with his/her new housemates"		
Agree	56	82.3
Disagree	8	11.8
Missing	4	5.9

Changes in Relative since Transition

The survey respondents were asked what changes they had noticed in the former JDC resident since transition; the possible responses were either more difficulty, no change, or improvements in the following areas: (1) emotions and moods, (2) daily living skills, (3) participation in activities, (4) relations with people, (5) community participation, and (6) choice (see Figure 22, next page). The majority of respondents indicated that they saw "no change" in the former JDC resident. At least a third of respondents saw "improvement" in the former JDC resident's daily living skills (37.0%), participation in activities (32.1%), and relations with people (30.2%). Approximately 20% of respondents (19.6%) indicated that the former JDC resident had "more difficulty" with their emotions and moods.

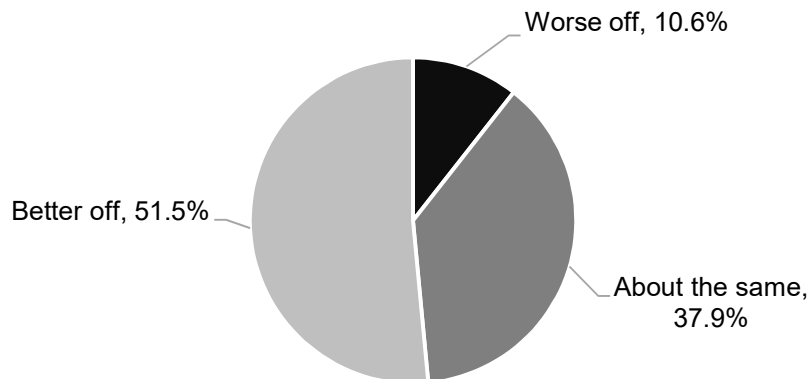
Figure 22: Since moving from JDC, what changes have survey respondents seen in the former JDC resident?



How is the former JDC resident faring compared to their time at JDC?

Survey respondents (n=66) were asked if they believed the former JDC resident to be better or worse off compared to that person’s time at JDC (Figure 23, next page). Most respondents (51.5%) felt that the former JDC resident was “better off” and 37.9% said “about the same.” Only 10.6% felt the former JDC resident was “worse off” after moving from JDC.

Figure 23: As compared to when the former JDC resident lived at JDC, is she/he better/worse off now? (n=66)



The responses to this question were about the same when the respondent was a family member (n=57) of the former JDC resident. The majority of respondents (50.9%) stated that the former JDC resident was “better off” now, compared to 38.6% who responded “about the same” and 10.5% who responded that the former JDC resident was “worse off.”

OUTCOMES

Methods

The Illinois Department of Human Services, Division of Developmental Disabilities gathered data on individuals who transitioned from JDC to either a 24 hour CILA (n=107) or an Intermediate Care Facility for Developmental Disability (ICF/DD), (n=18). In order to maintain confidentiality, this data set was de-identified before it was provided to the research team. The data includes demographic information as well as indicators for whether the former JDC resident had (1) visited an emergency room (ER) and reasons for the ER visit and (2) been involved with the police and reasons for police involvement. This section of the report focuses on only former JDC residents who transitioned to a CILA (n=107) and the data is complete through November 30, 2013.

Results

Emergency Room Use

Of the 107 former JDC residents who moved to a CILA most did not visit an ER (52.4%); over a quarter (27.1%) only visited the ER once and 21.5% of former JDC residents visited an ER room more than once. Three individuals are outliers in this data, with two visiting an ER five times and another visiting an ER 12 times. Figure 24 illustrates the number of times that each former JDC resident visited the ER.

Figure 24: Number of ER visits per former JDC resident (n=107)

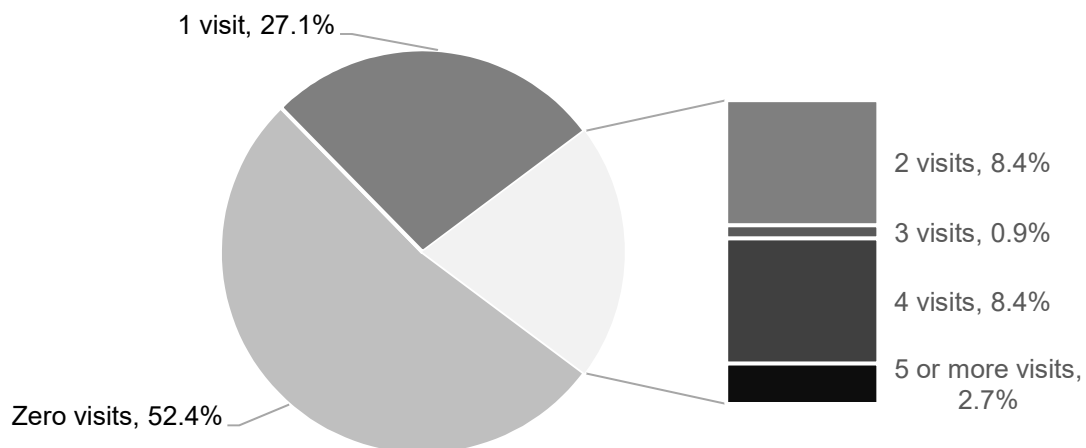
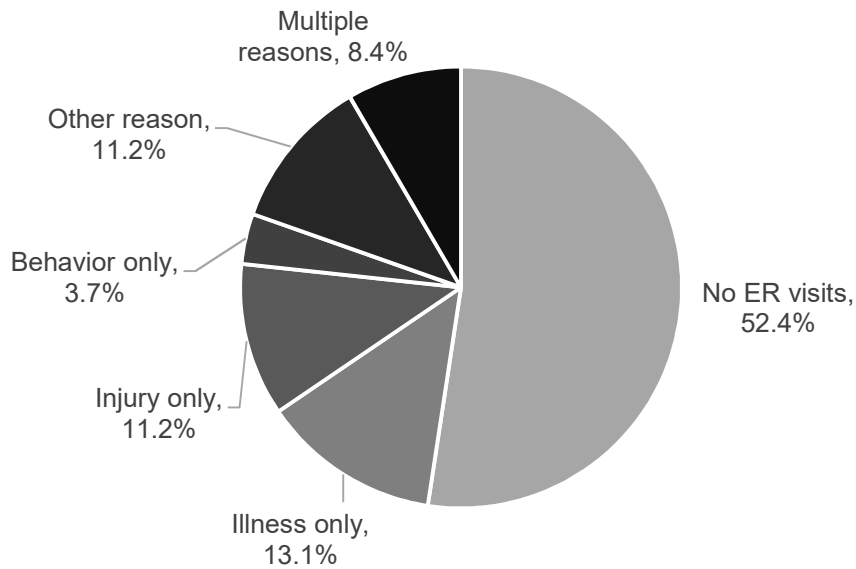


Figure 25 (next page) illustrates the frequency of the reasons that a former JDC resident visited an ER. This data is at the person-level and not for each ER visit. For example, in the data, one person may have had 4 ER visits, and the data field for “behavior” may be checked; however, the research team cannot determine how many of those four visits were for “behavior.” The reasons that a person visited the ER included: Illness only (13.1%), Injury only (11.2%), Behavior only (3.7%), and “Other” reasons (11.2%). Additionally, 8.4% of individuals visited an ER for multiple reasons. Without a comparison group, the research team cannot determine whether rates of ER visits differ from other people with developmental disabilities, in SODCs or other settings.

Examples of “Illness” as a reason for an ER visit included fever, vomiting, and urinary tract infections. “Injury” reasons included broken bones, lacerations, and

contusions. “Behavior” reasons included physical aggression towards self and others, property destruction, and suicidal intentions. Examples of “other” reasons include seizure and nose bleeds.

Figure 25: Reason for ER use (n=107)



Police Involvement

Of the 107 former JDC residents who moved to a CILA the vast majority (85.0%) did not have any police involvement. Just over five percent (7.5%) of former JDC residents had only one instance of police involvement; 3.7% had two instances of police involvement; and 3.8% had three or more instances of police involvement (two former JDC residents had three instances; one former resident had four instances; and one other former resident had six instances of police involvement). Figure 26 (next page) illustrates the number of times each former resident was involved with the police. Without a comparison group, the research team cannot determine whether rates of police involvement differ from other people with developmental disabilities, in SODCs or other settings.

Figure 26: Number of Instances of Police Involvement per former JDC Resident (n=107)

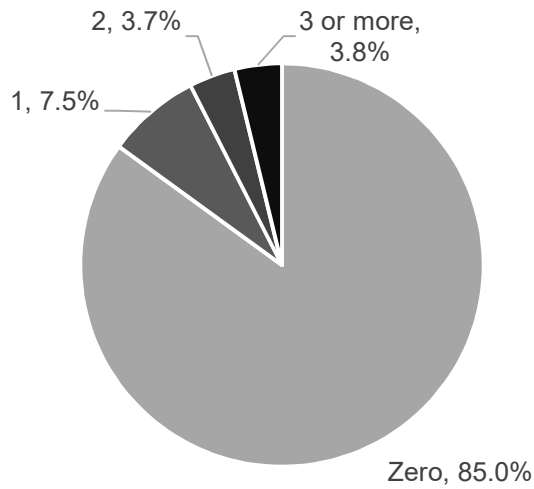
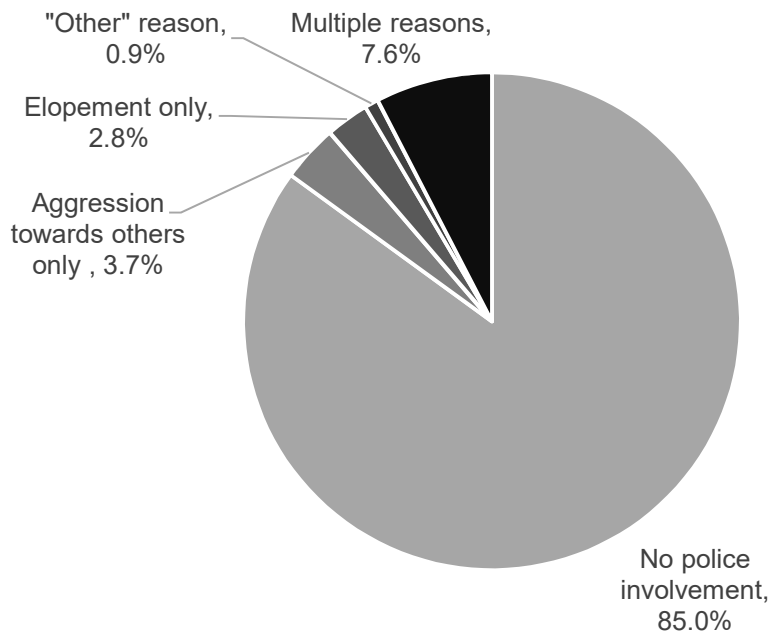


Figure 27 illustrates the frequency of the reasons that each former JDC resident was involved with the police (n=107). Again, this data is by person and not by instance of police involvement. The primary reasons individuals had police involvement included: Aggression towards others (3.7%), Elopement (2.8%), and "Other" reason (0.9%); 7.6% of individuals had multiple reasons for police involvement.

Figure 27: Reasons for Police Involvement (n=107)



DISCUSSION

This study sought to (1) survey guardians of individuals who transitioned from JDC, approximately one year after the initial survey and (2) examine emergency room (ER) use and police involvement for individuals who transitioned to a CILA.

In Illinois, like the rest of the United States, many individuals with developmental disabilities are transitioning from SODCs to living in smaller, community settings (Braddock et al, 2015). The number of individuals residing in settings with six or fewer residents has risen from just under 4,000 in 1996 to almost 15,000 in 2013. The closure of JDC was different from the closure of previous SODCs such as Howe and Lincoln, because the majority (63.9%) of former JDC residents transitioned to a CILA while just 23.7% transitioned to another SODC; during the Howe and Lincoln closures, the majority of individuals transitioned to another SODC (76.4% and 70.5% respectively) (Vasudevan, Rizzolo, Heller, & Lulinski. 2015).

Studies have shown that some individuals who transitioned to the community demonstrated “challenging” behaviors (Lakin, Larson, & Kim, 2011; Larson & Lakin, 2012). Some guardians indicated that they perceived that their relative had more difficulty with emotions/moods. However, the results of this report showed that most survey respondents report either no change or improvements in these behaviors. Additional research on these behaviors is needed, especially in comparison with people who moved to other settings.

Of the 107 individuals transitioning from JDC to a CILA 85% had no police involvement. Lulinski (2014) surveyed and interviewed community providers across Illinois about what types of community services they utilize as mental/behavioral supports. The majority of providers who were surveyed (n=59) used police/911/emergency medical services for: harm to others (75.4%), harm to self (69.2%), and property destruction (52.3%). Some of the providers suggested a need for increased access to behavioral services (Lulinski, 2014). For example, one provider stated that they wanted an increase in “Short term crisis units that allow for drug holidays and 24 hour professional medical oversight for medication changes.” By having increased access to services, individuals will be able to adjust to their new setting.

Additional research is also needed on police involvement, especially in comparison with people who moved to other settings.

Of the 107 individuals who transitioned from JDC to a CILA, 52.4% did not visit an ER. However, the primary reason for ER visits were for illness, injury, and behavior. This finding is similar to other studies (Janicki et al. 2002). Communities need to have improved capacity to provide healthcare for people with developmental disabilities. This could enable healthcare professionals to manage an individual's medication, recognize the signs of an illness, and hopefully prevent an illness. However, physicians should be educated more on how to care for people with developmental disabilities (Wilkinson, Dreyfus, Cerreto, & Bokhour 2012). Again, it is important to note that there was no data available for a comparison group; nor was data available regarding ER services before the individual transitioned, so that the impact of an individual transitioning from JDC to a CILA cannot be determined. Furthermore, when the individual was a JDC resident, use of the ER was likely less because healthcare services were available onsite at JDC.

CONCLUSION

Generally, individuals who transitioned from JDC to the community have experienced positive outcomes. Regardless of relationship status, the majority of respondents (both state guardians and family members) were satisfied with the former JDC resident's current living situation. Most respondents indicated that the living situation and behaviors of the former JDC resident were about the same or had improved following the transition to the community. The majority did not have any police involvement or ER visits. Future studies need to examine detailed reasons for ER use and police involvement for individuals living in the community in comparison with people with developmental disabilities in SODCs and other settings.

RECOMMENDATIONS

- Support individuals before and during closure:
 - Arrange for an onsite visit(s) to the new home whenever possible and include items familiar to the individual to provide a normalizing experience;
 - Use technology (e.g., webcam), written materials (e.g., brochures), or other media (e.g., DVDs or photo albums) to provide virtual tours of homes and staff introductions when individual is unable to visit potential placement;
 - Address pending moves using a calendar, or other visual aids, to provide residents with cues about their move date and that of their housemates; and
 - Support individuals on moving day by having SODC staff members, relatives, and familiar items accompany the individual to their new homes to provide a more welcoming and assuring experience.

- Facilitate improved communication with families:
 - Get families/guardians involved earlier in the closure process;
 - Explore the continuum of residential supports and services available with guardians;
 - Identify a point person for guardians to contact with questions or concerns;
 - Proactively contact guardians to discuss needs such as completion of paperwork and assistance to visit potential new placements;
 - Use a listserv or other technology to provide accurate and consistent information;
 - Reconsider use of the hotline implemented during the Howe closure;
 - Provide incentives to organizations to coordinate travel to potential new homes for elderly and/or disabled parents/guardians so that they may tour the setting; and
 - Use technology (e.g., webcam), written materials (e.g., brochures), or visual media (e.g., DVDs or photo albums) to provide virtual tours of homes and staff introductions when guardian is unable to visit potential placement.

- Improve communication with SODC staff:
 - Hold regularly scheduled campus-wide and individual unit meetings;
 - Use a calendar for PCP meetings and individual moving dates; and
 - Identify a key contact person for SODC staff to contact with questions.

- Improve communication with receiving provider agencies:
 - Identify a key contact at the SODC for agency provider staff to ask questions;
 - Work with providers to determine individual move-in dates;

- Use a checklist for the SODC staff and receiving agency staff to complete upon individual's arrival which includes items such as medications, medical equipment, etc., to assure that individuals have the supplies mentioned in the ISP and for which they have physicians' orders;
 - Alert agencies prior to move about items individual may need (clothing, coat, toothbrush, etc.); and
 - Invest in electronic records to facilitate information sharing between SODCs and receiving providers while alleviating opportunity for loss or alteration of records.
- Increase flexibility of closure date:
- Identify reasonable yet firm date. Educate families earlier on about the benefits of community living.
 - Have families who have already gone through the transition process be available to talk to other families
 - Incentivize key SODC staff to remain until campus is closed.
 - Use staff from other SODCs to assist with administrative functions during closure to alleviate staff stress and overtime.

APPENDIX A

**An Evaluation of the
Closure of Jacksonville Developmental Center
Family/Guardian Satisfaction Survey
The University of Illinois
Institute on Disability and Human Development**

1.	What is your relation to the individual who moved out of Jacksonville?					
	<input type="checkbox"/>	Parent	<input type="checkbox"/>	Grandparent	<input type="checkbox"/>	Brother/Sister
	<input type="checkbox"/>	Aunt/Uncle	<input type="checkbox"/>	Niece/Nephew	<input type="checkbox"/>	Cousin
	<input type="checkbox"/>	Friend	<input type="checkbox"/>	Public Guardian	<input type="checkbox"/>	Other _____

2.	What is your age?	
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3.	What is your gender?	<input type="checkbox"/>	Male	<input type="checkbox"/>	Female
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4.	What is your race?					
	<input type="checkbox"/>	White	<input type="checkbox"/>	Black	<input type="checkbox"/>	American Indian or Alaskan Native
	<input type="checkbox"/>	Asian American	<input type="checkbox"/>	Native Hawaiian or Pacific Islander	<input type="checkbox"/>	Two or More Races
	<input type="checkbox"/>	Other _____				

5.	What is your ethnicity?					
	<input type="checkbox"/>	Hispanic	<input type="checkbox"/>	Non-Hispanic		

6.	What is your highest level of education?					
	<input type="checkbox"/>	Less than 12 th grade	<input type="checkbox"/>	High School/GED	<input type="checkbox"/>	Some college/Associates degree
	<input type="checkbox"/>	Bachelors degree	<input type="checkbox"/>	Masters degree	<input type="checkbox"/>	Doctorate
	<input type="checkbox"/>	Other: _____				

7.	How old is the person who moved out of Jacksonville?	
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8.	What is the gender of the person who moved out of Jacksonville?			
	<input type="checkbox"/>	Male	<input type="checkbox"/>	Female

9.	What is the race of the person who moved out of Jacksonville?					
	<input type="checkbox"/>	White	<input type="checkbox"/>	Black	<input type="checkbox"/>	American Indian or Alaskan Native
	<input type="checkbox"/>	Asian American	<input type="checkbox"/>	Native Hawaiian or Pacific Islander	<input type="checkbox"/>	Two or More Races
	<input type="checkbox"/>	Other _____				

10.	What is the ethnicity of the person who moved out of Jacksonville?			
	<input type="checkbox"/>	Hispanic	<input type="checkbox"/>	Non-Hispanic

11.	How many years did s/he live at Jacksonville?					
	<input type="checkbox"/>	0 - 5	<input type="checkbox"/>	6 - 10	<input type="checkbox"/>	11 - 15
	<input type="checkbox"/>	16 - 20	<input type="checkbox"/>	21 - 25	<input type="checkbox"/>	26 - 30
	<input type="checkbox"/>	31 or more				

12.	While living at Jacksonville, did the person who moved use any of the following? (check all that apply)					
	<input type="checkbox"/>	Mobility equipment (wheelchair, walker, etc.)	<input type="checkbox"/>	Seating equipment (seat cushion, back cushion, etc.)	<input type="checkbox"/>	Communication equipment (Dynavox, communication board, etc.)

13.	Does the person who moved out of Jacksonville need assistance with any of the following activities of daily living? (check all that apply)					
	<input type="checkbox"/>	Bathing	<input type="checkbox"/>	Dressing	<input type="checkbox"/>	Transferring
	<input type="checkbox"/>	Toileting	<input type="checkbox"/>	Eating	<input type="checkbox"/>	Walking
	<input type="checkbox"/>	Getting Outside	<input type="checkbox"/>	Preparing Meals	<input type="checkbox"/>	Shopping for Groceries
	<input type="checkbox"/>	Managing Money	<input type="checkbox"/>	Using Telephone	<input type="checkbox"/>	Doing Heavy Housework
	<input type="checkbox"/>	Doing Light Housework	<input type="checkbox"/>	Getting to Places Outside	<input type="checkbox"/>	Managing Medication
	<input type="checkbox"/>	Behavioral Support	<input type="checkbox"/>	Communication	<input type="checkbox"/>	Other: _____

14.	Where did s/he live before Jacksonville?			
<input type="checkbox"/>	Another State Operated Developmental Center (SODC)	<input type="checkbox"/>	An Intermediate Care Facility for persons with Developmental Disabilities (ICF/DD)	
<input type="checkbox"/>	A Community Integrated Living Arrangement (CILA)	<input type="checkbox"/>	A Nursing Home	
<input type="checkbox"/>	Family home	<input type="checkbox"/>	Other: _____	

15.	How satisfied were you with the services s/he received at Jacksonville?			
<input type="checkbox"/>	Very satisfied	<input type="checkbox"/>	Somewhat satisfied	
<input type="checkbox"/>	Somewhat dissatisfied	<input type="checkbox"/>	Very dissatisfied	

16.	Initially, how satisfied were you with the decision to close Jacksonville?			
<input type="checkbox"/>	Very satisfied	<input type="checkbox"/>	Somewhat satisfied	
<input type="checkbox"/>	Somewhat dissatisfied	<input type="checkbox"/>	Very dissatisfied	

17.	<u>Prior</u> to the Jacksonville closure, how much did you agree with the following statement: <i>My relative would benefit from a move out of an institution and into a community placement:</i>			
<input type="checkbox"/>	Strongly agree	<input type="checkbox"/>	Somewhat agree	
<input type="checkbox"/>	Somewhat disagree	<input type="checkbox"/>	Strongly disagree	

18.	How satisfied have you been with the closure/movement process?			
<input type="checkbox"/>	Very satisfied	<input type="checkbox"/>	Somewhat satisfied	
<input type="checkbox"/>	Somewhat dissatisfied	<input type="checkbox"/>	Very dissatisfied	

19.	How satisfied are you <u>now</u> with the decision to close Jacksonville?			
<input type="checkbox"/>	Very satisfied	<input type="checkbox"/>	Somewhat satisfied	
<input type="checkbox"/>	Somewhat dissatisfied	<input type="checkbox"/>	Very dissatisfied	

20.	Do you feel your opinions were respected during the transition process?			
	<input type="checkbox"/>	Strongly agree	<input type="checkbox"/>	Somewhat agree
	<input type="checkbox"/>	Somewhat disagree	<input type="checkbox"/>	Strongly disagree

21.	How do you feel about the pace of the closure process?					
	<input type="checkbox"/>	It moved too quickly	<input type="checkbox"/>	It moved at a good pace	<input type="checkbox"/>	It moved too slowly

22.	<u>Currently</u> , how much do you agree with the following statement: <i>My relative would benefit from a move out of an institution and into a community placement</i>			
	<input type="checkbox"/>	Strongly agree	<input type="checkbox"/>	Somewhat agree
	<input type="checkbox"/>	Somewhat disagree	<input type="checkbox"/>	Strongly disagree

23.	<u>Prior</u> to the Jacksonville closure, had you ever received information on other residential options?		<input type="checkbox"/>	Yes	<input type="checkbox"/>	No
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24.	Did you receive adequate information on service providers about which to make a choice?		<input type="checkbox"/>	Yes	<input type="checkbox"/>	No
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25.	Did you visit your relative's new placement before making a decision that he (she) would move there?		<input type="checkbox"/>	Yes	<input type="checkbox"/>	No
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26.	How many agencies did you visit before making a placement decision?									
	<input type="checkbox"/>	None	<input type="checkbox"/>	1-2	<input type="checkbox"/>	3-4	<input type="checkbox"/>	5-6	<input type="checkbox"/>	More than 6

27.	Did your relative visit the new placement before moving in?		<input type="checkbox"/>	Yes	<input type="checkbox"/>	No
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28.	How many times did your relative visit the new placement <u>prior</u> to moving in?								
<input type="checkbox"/>	None	<input type="checkbox"/>	1-2	<input type="checkbox"/>	3-4	<input type="checkbox"/>	5-6	<input type="checkbox"/>	More than 6

29.	How many of his/her visits to the new placement were short visits, lasting less than 3 hours?								
<input type="checkbox"/>	None	<input type="checkbox"/>	1-2	<input type="checkbox"/>	3-4	<input type="checkbox"/>	5-6	<input type="checkbox"/>	More than 6

30.	How many of his/her visits were day visits, lasting more than 3 hours but not overnight?								
<input type="checkbox"/>	None	<input type="checkbox"/>	1-2	<input type="checkbox"/>	3-4	<input type="checkbox"/>	5-6	<input type="checkbox"/>	More than 6

31.	How many of his/her visits to the new placement were overnight visits or longer?								
<input type="checkbox"/>	None	<input type="checkbox"/>	1-2	<input type="checkbox"/>	3-4	<input type="checkbox"/>	5-6	<input type="checkbox"/>	More than 6

32.	Did you receive timely updates on your relative's transition from Jacksonville?	<input type="checkbox"/>	Yes	<input type="checkbox"/>	No
-----	---	--------------------------	-----	--------------------------	----

33.	How satisfied were you with your relative's Transition Plan?				
<input type="checkbox"/>	Very satisfied	<input type="checkbox"/>	Somewhat satisfied	<input type="checkbox"/>	Satisfied
<input type="checkbox"/>	Somewhat dissatisfied	<input type="checkbox"/>	Very dissatisfied	<input type="checkbox"/>	I was not aware my relative had a transition plan

34.	What was your first choice of settings?		
<input type="checkbox"/>	Another State Operated Developmental Center (SODC)	<input type="checkbox"/>	An Intermediate Care Facility for persons with Developmental Disabilities (ICF/DD)
<input type="checkbox"/>	A Community Integrated Living Arrangement (CILA)	<input type="checkbox"/>	A Nursing Home
<input type="checkbox"/>	Other: _____		

35.	Did your relative move to your first choice of settings?	<input type="checkbox"/>	Yes	<input type="checkbox"/>	No
	If not, what were the reasons?				

36.	To what type of setting did your relative move?				
	<input type="checkbox"/>	Another State Operated Developmental Center (SODC)	<input type="checkbox"/>	An Intermediate Care Facility for persons with Developmental Disabilities (ICF/DD)	
	<input type="checkbox"/>	A Community Integrated Living Arrangement (CILA)	<input type="checkbox"/>	A Nursing Home	
	<input type="checkbox"/>	Other: _____			

37.	Is your relative's current residence temporary or permanent?					
	<input type="checkbox"/>	Temporary	<input type="checkbox"/>	Permanent	<input type="checkbox"/>	I am not sure/ I don't know
	If the placement is temporary, please explain why.					

38.	How satisfied are you with your relative's <u>current</u> living situation?				
	<input type="checkbox"/>	Very satisfied	<input type="checkbox"/>	Somewhat satisfied	
	<input type="checkbox"/>	Somewhat dissatisfied	<input type="checkbox"/>	Very dissatisfied	

39.	As compared to when your relative lived at Jacksonville, do you think s/he is better or worse off <u>now</u> ?					
	<input type="checkbox"/>	Significantly better	<input type="checkbox"/>	Somewhat better	<input type="checkbox"/>	About the same
	<input type="checkbox"/>	Somewhat worse	<input type="checkbox"/>	Significantly worse		

40.	How would you characterize the neighborhood/community that your relative moved into?			
	<input type="checkbox"/>	Very safe	<input type="checkbox"/>	Somewhat safe
	<input type="checkbox"/>	Not very safe	<input type="checkbox"/>	Not safe at all

41.	The people who work in my relative's present home are as knowledgeable, as skillful, and as supportive as the staff who worked at Jacksonville.			
	<input type="checkbox"/>	Strongly agree	<input type="checkbox"/>	Somewhat agree
	<input type="checkbox"/>	Somewhat disagree	<input type="checkbox"/>	Strongly disagree

42.	I believe that my relative receives adequate supervision at his/her new home:			
	<input type="checkbox"/>	Strongly agree	<input type="checkbox"/>	Somewhat agree
	<input type="checkbox"/>	Somewhat disagree	<input type="checkbox"/>	Strongly disagree

43.	Services needed by my relative are available to him/her in their new home:			
	<input type="checkbox"/>	Strongly agree	<input type="checkbox"/>	Somewhat agree
	<input type="checkbox"/>	Somewhat disagree	<input type="checkbox"/>	Strongly disagree

44.	My relative likes the staff that work with him/her at the new placement			
	<input type="checkbox"/>	Strongly agree	<input type="checkbox"/>	Somewhat agree
	<input type="checkbox"/>	Somewhat disagree	<input type="checkbox"/>	Strongly disagree
	<input type="checkbox"/>	I don't know/ am not sure		

45.	My relative gets along with his/her new housemates:			
	<input type="checkbox"/>	Strongly agree	<input type="checkbox"/>	Somewhat agree
	<input type="checkbox"/>	Somewhat disagree	<input type="checkbox"/>	Strongly disagree
	<input type="checkbox"/>	My relative does not have housemates		

46.	<u>Currently</u> , does the person who moved out of Jacksonville use any of the following? (check all that apply)					
	<input type="checkbox"/>	Mobility equipment (wheelchair, walker, etc.)	<input type="checkbox"/>	Seating equipment (seat cushion, back cushion, etc.)	<input type="checkbox"/>	Communication equipment (Dynavox, communication board, etc.)

47.	While at Jacksonville, in which of the following activities did your relative participate in during the day? (check all that apply)					
	<input type="checkbox"/>	Developmental Training/Day Program	<input type="checkbox"/>	Employment in the community		
	<input type="checkbox"/>	Volunteering in the community	<input type="checkbox"/>	N/A; I don't know		

48.	While at Jacksonville, did your relative have access to any of the following? (check all that apply)					
	<input type="checkbox"/>	Computer	<input type="checkbox"/>	Internet		
	<input type="checkbox"/>	Telephone	<input type="checkbox"/>	N/A; I don't know		

49.	While at Jacksonville, did your relative indicate a desire to use any of the following? (check all that apply)					
	<input type="checkbox"/>	Computer	<input type="checkbox"/>	Internet		
	<input type="checkbox"/>	Telephone	<input type="checkbox"/>	N/A; I don't know		

50.	<u>Currently</u> , does your relative have access to any of the following? (check all that apply)					
	<input type="checkbox"/>	Computer	<input type="checkbox"/>	Internet		
	<input type="checkbox"/>	Telephone	<input type="checkbox"/>	N/A; I don't know		

51.	<u>Currently</u> , does your relative indicate a desire to use any of the following? (check all that apply)			
	<input type="checkbox"/>	Computer	<input type="checkbox"/>	Internet
	<input type="checkbox"/>	Telephone	<input type="checkbox"/>	N/A; I don't know

52.	<u>Currently</u> , does your relative have access to any of the following? (check all that apply)			
	<input type="checkbox"/>	Personal e-mail address	<input type="checkbox"/>	Social media account (Facebook, Twitter)
	<input type="checkbox"/>	Tablet (iPad)	<input type="checkbox"/>	Cell phone / Smart phone (iPhone, Droid)
	<input type="checkbox"/>	Webcam software (Skype)	<input type="checkbox"/>	N/A; I don't know

53.	<u>Currently</u> , does your relative express a desire to have access to any of the following? (check all that apply)			
	<input type="checkbox"/>	Personal e-mail address	<input type="checkbox"/>	Social media account (Facebook, Twitter)
	<input type="checkbox"/>	Tablet (iPad)	<input type="checkbox"/>	Cell phone / Smart phone (iPhone, Droid)
	<input type="checkbox"/>	Webcam software (Skype)	<input type="checkbox"/>	N/A; I don't know

54.	In which of the following activities does your relative participate in during the day at his/her new home? (check all that apply)			
	<input type="checkbox"/>	Developmental Training/Day Program	<input type="checkbox"/>	Employment in the community
	<input type="checkbox"/>	Volunteering in the community	<input type="checkbox"/>	N/A; I don't know

55.	How satisfied are you with these activities?			
	<input type="checkbox"/>	Very satisfied	<input type="checkbox"/>	Somewhat satisfied
	<input type="checkbox"/>	Somewhat dissatisfied	<input type="checkbox"/>	Very dissatisfied

56.	Was your relative able to remain at the same Developmental Training (DT) site that they went to while living at Jacksonville?					
	<input type="checkbox"/>	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	N/A

57.	While your relative lived at Jacksonville, how frequently did you visit him/her?					
	<input type="checkbox"/>	At least once a week	<input type="checkbox"/>	At least once a month	<input type="checkbox"/>	3-4 times/year
	<input type="checkbox"/>	Once a year	<input type="checkbox"/>	Less than once a year	<input type="checkbox"/>	Not at all

58.	How long did it typically take you to travel from your home to Jacksonville?							
	<input type="checkbox"/>	Less than 30 minutes	<input type="checkbox"/>	30 min – 1 hour	<input type="checkbox"/>	1 – 1 ½ hours	<input type="checkbox"/>	1 ½ - 2 hours
	<input type="checkbox"/>	2 – 2 ½ hours	<input type="checkbox"/>	2 ½ - 3 hours	<input type="checkbox"/>	3 - 3 ½ hours	<input type="checkbox"/>	More than 3 ½ hours
	<input type="checkbox"/>	N/A; I don't know						

59.	How frequently do you visit him/her <u>now</u> ?					
	<input type="checkbox"/>	At least once a week	<input type="checkbox"/>	At least once a month	<input type="checkbox"/>	3-4 times/year
	<input type="checkbox"/>	Once a year	<input type="checkbox"/>	Less than once a year	<input type="checkbox"/>	Not at all

60.	How long does it take you to travel from your home to your relative's new home?							
	<input type="checkbox"/>	Less than 30 minutes	<input type="checkbox"/>	30 min – 1 hour	<input type="checkbox"/>	1 – 1 ½ hours	<input type="checkbox"/>	1 ½ - 2 hours
	<input type="checkbox"/>	2 – 2 ½ hours	<input type="checkbox"/>	2 ½ - 3 hours	<input type="checkbox"/>	3 - 3 ½ hours	<input type="checkbox"/>	More than 3 ½ hours
	<input type="checkbox"/>	N/A; I don't know						

61.	How would you compare your current commute <u>now</u> to the commute to Jacksonville?					
	<input type="checkbox"/>	Significantly better	<input type="checkbox"/>	Somewhat better	<input type="checkbox"/>	About the same
	<input type="checkbox"/>	Somewhat worse	<input type="checkbox"/>	Significantly worse		

62. Additional comments: (Additional pages may be attached for further comments)

Please share your opinion of how your relative is doing now:

Have you observed any changes in your relative since the transition from Jacksonville (e.g., personal care, behavior problems, friends, physical health, emotional well-being)? If so, please explain.

Please share any additional information about the transition process, your relative's adjustment to his/her new home, etc.

Please describe what effect, if any, the closure of Jacksonville has had on your family, including any examples that would support your description.

How did you choose your relative's new home?

APPENDIX B

Interview Guide for Key Agency Staff Evaluation of Jacksonville Developmental Center Closure

Areas of Inquiry

1. Closure Process

- a. Describe your agency's role in the closure of JDC.
- b. How appropriate do you feel the closure timeline was for the successful closure of JDC?
 - i. Was enough time given to successfully transition residents out? If not, are there suggestions for different timelines?
- c. What is the first priority in an SODC closure from your point of view?
- d. Thinking of the JDC closure specifically, what was done well?
 - i. What was not done well?
- e. Did you know who the key contact in charge of the closure was? Who did you contact if you had questions regarding procedures or policies, or other issues?
- f. To what extent did you work with families?

2. Communication Among System Partners

- a. How effective was communication system partners involved in the closure?
- b. What recommendations, if any, would you suggest in terms of the way communications were coordinated for future program initiatives?

3. Resident Relocation

- a. How satisfied are you with the tools used to determine community placement of SODC residents?
- b. **(for ISSA)**: How did you find out about available residential options?
 - i. Were there any PR materials that you found useful in this process?
- c. **(for providers)**: How were support needs of the individual(s) conveyed to you?
 - i. Looking back do you feel that the needs were adequately conveyed?
 - ii. Do you feel that your agency receives an appropriate rate with which to serve the individual's service and support needs?
- d. What recommendations, if any, do you have regarding the planned transition of individuals with dual diagnosis out of SODCs?

4. Quality Assurance

- a. What recommendations, if any, would you give to improve how SODCs in the State are closed in the future?
- b. Can you recommend any other stakeholder we should interview regarding the closure process?

APPENDIX C

University of Illinois at Chicago Research Information and Consent for Participation in Social Behavioral Research An Evaluation of the Jacksonville Developmental Center Closure – Former Resident Interviews

You are being asked permission for your family member/ward to participate in a research study. Researchers are required to provide a consent form such as this one to tell you about the research, to explain that taking part is voluntary, to describe the risks and benefits of participation, and to help you to make an informed decision. You should feel free to ask the researchers any questions you may have.

Principal Investigator Name and Title: Mary Kay Rizzolo, PhD
Department and Institution: Department and Institution: Disability and Human Development, University of Illinois at Chicago
Address and Contact Information: 1640 West Roosevelt Road, Room 436, Chicago, IL 60608

Sponsor: Illinois Department of Public Health

The University of Illinois at Chicago has teamed up with the Department of Human Services to conduct an evaluation of the closure of Jacksonville Developmental Center. Since your family member (or ward) lived at Jacksonville during the time of closure, we would like to talk to your family member about how well the closure process worked. Your family member's input will help us plan for future transitions from state operated developmental centers (SODCs) into the community. We are asking people with developmental disabilities who lived at Jacksonville Developmental Center to participate in interviews to share their experience with the closure process.

Why am I being asked?

You have been asked to participate in the research because your family member (or ward) lived at Jacksonville Developmental Center at the time of closure.

We are asking you for permission to talk to your family member or ward who lived at Jacksonville Developmental Center during the time of its closure to determine their willingness to participate in a research study about the closure of Jacksonville Developmental Center. We would like to interview them to obtain their perspective on the decision to close Jacksonville, their input into their transition plan, issues regarding the actual move, the impact of the closure on their relationships and their quality of life, and their satisfaction with their current placement.

Your family member's (or ward's) participation in this research is voluntary. Their decision whether or not to participate will not affect their current or future dealings with the University of Illinois at Chicago or the Department of Human Services. **If they decide to participate, they are free to withdraw at any time without affecting that relationship.**

Approximately 181 subjects may be involved in this research at UIC.

What is the purpose of this research?

Researchers would like to learn more about the closure process of state operated developmental centers in Illinois. We would like to include the perspective of the individuals living in these facilities during the time of their closure in our research. We would like to learn about their satisfaction with the closure process, the impact the closure had on their relationships and quality of life, and their satisfaction with their current residential setting.

What procedures are involved?

This interview will be performed at a location selected by your family member (or ward), such as their home or work site/day program. We will go to the location they select at the time that best works for them in a place they feel comfortable. The interview will take approximately one hour to complete and will be audio recorded. The recordings will be used by the researchers at UIC to develop a report for DHS. No names will be given in the report. All comments will be anonymous. Interviewees will receive \$20 in cash to reimburse them for their time.

What are the potential risks and discomforts?

We believe the material discussed in the one on one interview presents no more risk of harm than you would experience in everyday life. However, there is the risk of a loss of privacy (revealing to others that your family member is taking part in this study) or confidentiality (revealing information about your family member to others to whom they have not given permission to see this information). The UIC researchers will take every precaution, however, to ensure that no loss of privacy or confidentiality will occur. No real names will be used in the report and audio recordings will only be available to key researchers. No names will be used in the audio tapes to further ensure participant privacy.

Are there benefits to taking part in the research?

Taking part in this research study may not benefit you or your family member personally, but we may learn new things that will help others. This study is designed to learn more about the closure of state operated developmental centers in the state of Illinois. The study results may be used to help other people in the future and assist the Department of Human Services in policy development and implementation.

What other options are there?

Your family member has the option to not participate in this study.

What about privacy and confidentiality?

The people who will know that your family member is a research subject are members of the research team. Otherwise, information about them will only be disclosed to others with your written permission, or, if necessary to protect their rights or welfare or if required by law.

Audio from interviews with your family member will be digitally recorded. Digital audio will be stored on pass-word protected computers and informed consent documents will be stored in locked file cabinets. Only members of the research team will have access to audio files. Audio files will be transcribed. Transcriptions will not contain names or other any other information that could reveal your family member's identity. Audio files will be destroyed following the completion of the study, which is expected to be within one year.

When the results of the research are published or discussed in conferences, no information will be included that would reveal your family member's identity.

The UIC IRB and the State of Illinois may review identification for auditing purposes.

What are the costs for participating in this research?

There are no costs for participating in this research.

Will my family member/ward be reimbursed for any of my expenses or paid for participation in this research?

Your family member will receive \$20 in cash for his/her participation in this interview. If the individual decides to withdraw participation from the study, or if the researcher withdraws the participant from the study, they will still receive the money. The money will be given upon completion of the interview or upon withdrawal.

Can I withdraw or be removed from the study?

If your family member/ward decides to participate, s/he is free to withdraw consent and discontinue the interview at any time. S/he has the right to leave the interview at any time without penalty. The Researchers have the right to stop the interview without your consent if they believe it is in the best interests of your family member/ward. The Researchers also have the right to stop the interview without your consent if, during the course of the interview, your family member/ward becomes emotionally distraught in any way. In the event you withdraw or are asked to leave the study, or your family member/ward asks to leave the interview, s/he will still be compensated as described above.

Who should I contact if I have questions?

Contact the researchers Mary Kay Rizzolo (312-413-8879; mrizzo3@uic.edu) or Amie Lulinski-Norris (312-996-1792; anorri4@uic.edu) if you have any questions about this study or your part in it or if you have questions, concerns or complaints about the research.

What are my rights as a research subject?

If you feel you or your family member/ward have not been treated according to the descriptions in this form, or if you have any questions about your rights as a research subject, including questions, concerns, complaints, or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at 312-996-1711 or 1-866-789-6215 (toll-free) or e-mail OPRS at uicirb@uic.edu.

Remember:

Your participation and that of your family member/ward, in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

Signature of Subject or Legally Authorized Representative

I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research. I will be given a copy of this signed and dated form.

Print name of individual who will participate in interview

Signature of individual (or legal guardian)

Date

Printed Name

Signature of Research Personnel Obtaining Consent

Date (must be same as subject's)

Printed Name of Research Personnel Obtaining Consent

APPENDIX D

Evaluation of Jacksonville Developmental Center Closure

Interview Guidelines for Individuals who transitioned out of Jacksonville Developmental Center

Areas of Inquiry

1. The Transition

- a. How did you find out that Jacksonville was closing?
- b. How did you feel when you heard Jacksonville was closing?
 - Tell me about how you made the decision to move here.
 - a. Prompting questions:
 - Did you make the decision to move here?
 - Did you have enough information to make a decision about where to live?
 - Did you have enough time to make a decision about where to move?
 - Who helped you make the decision to move here?
 - How did they help you?
 - Did you visit (name of place individual is currently residing) before you moved here?
 - Did you talk with any other providers/agencies? Was it helpful to talk to them?
 - c. Did you move to your first choice?

2. Transition Plan

- a. Do you have a transition plan or person centered plan?
- b. Did you help create your transition plan?
 - What was your role in creating the plan?
 - What supports were provided?
 - Were you satisfied with your transition plan?
 - Do you feel that it met/addressed your needs? If not, why?

3. The Move

- a. Did you know who to talk to during the move if you had questions or concerns?
 - Were you satisfied with the help you received during your move?

- Did you feel like you knew what was happening during the time Jacksonville was closing? Did you feel like people communicated with you? (were you kept in the loop)?
- b. Is there anything that you can think of that might have made the move easier?
 - c. Did anyone call you or come see you to ask how you were doing after you moved to your new home?
 - If so, were they helpful?
 - Did you need them to follow up on any concerns?
 1. If so, did they follow up for you?

4. Relationships

- a. Did any of your friends from Jacksonville move here also?
- b. Do you keep in touch with friends that moved to other places from Jacksonville?
 - If so, how do you keep in touch with them?
 - If not, why not?
- c. Do you have access to a computer?
 - Do you have an email account?
 - Do you use Facebook or Twitter to keep in touch with friends?
 - Do you use a webcam to talk to friends/family?
 1. If not, ask, "Would you like access to any of these things?"
 2. If so, who decides when you can use it?
- d. Did you have any problems with your supports or services during your move to your new home?
- e. Have you made new friends at your new home?
- f. Are you satisfied with your relationships? (friends, family boyfriend/girlfriend)

5. Quality of Life (for individuals living in another SODC)

- a. Are you happy living here?
 - What do you like here?
 - Do you feel comfortable?
 - What do you wish was different?
 - Do you like the location of your present home?
 - a. Is it close to your family? Friends?
 - Do you feel like you have privacy at home?
 - Do you miss Jacksonville?

- b. Do you feel safe in your current/present residence/home/day program? In your community?
 - If you ever didn't feel safe, would you know who to tell?
 - Do you feel that your things are safe?
- c. Respect
 - Are staff respectful of you?
 - Do staff explain things to you in ways you understand?
- d. Do you use anything to help you get from place to place or talk with people (wheelchair, walker, communication board)?
 - Would you like something like that?
- e. How long do you think you'll stay here?
- f. What do you do during the day?
 - Do you have a job or volunteer?
 - Do you enjoy it?
 - Do you make enough money?
 - Are you involved in any type of programs here? What types (vocational, independent living skills, medication management, etc)?
 - Do you participate in activities of your choice in the community (go to the movies, park, events, etc.)
 1. If not, why not?
 2. Do you have spending money?
- g. Do you think you'd be interested in moving into the community?
 - What would you need to live in the community?
 - Do you know how to get what you need to live in the community?
 - Who do you talk to about moving into the community?
- h. Do you feel happy with your life? If not, is there something that you would change?

6. Quality of Life (for individuals living in the community)

- a. Are you happy living here?
 - Is living here what you expected?
 - a. What is different?
 - What do you like here?
 - What do you wish was different?
 - Do you like the location of your present home?

- a. Do you like the community? Is it close to your family?
Friends?
 - Do you feel like you have privacy in your new home?
 - Do you miss Jacksonville?
- b. Do you feel safe in your current/present residence/home/day program? In your community?
 - If you didn't feel safe, would you know who to tell?
 - Do you feel that your personal property is safe?
- c. Respect
 - Are staff respectful of you?
 - Do staff explain things to you in ways you understand?
- d. Do you use anything to help you get from place to place or talk with people (wheelchair, walker, communication board)?
 - Would you like something like that?
- e. How long do you think you'll stay here?
- f. What do you do during the day?
 - Do you have a job or volunteer?
 - Are you involved in any type of programs here? What types (vocational, independent living skills, medication management, etc)?
 1. Do you like what you do during the day?
 - Do you participate in activities of your choice in the community (go to the movies, park, events, etc.)
 1. If not, why not?
 2. Do you have spending money?
 3. Do you feel happy with your life? If not, why? What would you change?

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