
AN EVALUATION OF THE HOWE DEVELOPMENTAL CENTER CLOSURE

Results from a Survey of Family Members and Guardians
and Interviews with Individuals who Lived at Howe



*Sorensen, A., Rizzolo, M. C., Lulinski Norris, A., & Heller, T.
The Institute on Disability and Human Development
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*Prepared for the Illinois Department of Human Services
Division of Developmental Disabilities*

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CONTENTS

Introduction.....	6
Methods	7
Findings from Family/Guardian Survey	8
Respondent Demographics	8
Relationship Type	8
Age of Respondent.....	8
Respondent Gender.....	8
Respondent Race.....	8
Respondent Ethnicity	8
Respondent Education.....	9
Relative Age.....	10
Assistance Needs	10
Number of Years at Howe	12
Howe and the Decision to Close.....	13
Satisfaction with Services at Howe.....	13
Initial Satisfaction with Howe Closure Decision.....	15
Current Satisfaction with Decision to Close Howe.....	18
Change in Satisfaction with Decision to Close Howe	19
The Closure Process.....	21
Satisfaction with Closure Process Overall	21
Influence Over Transition	24
My Opinions were Respected	24
Speed of Closure Process.....	26
Placement Options	26
Perceived Benefits of Community Placement PRIOR to Closure	26
Current Perceived Benefits of Community Placement	28
Benefits of Community Placement Change	31
Information on Alternative Placements	33
Visiting Placement Options	33
Number of Agencies Visited Prior to Transition	33
Placement at Preferred Location	35

Transition Services.....	36
Transition Updates	38
Transition Plans	38
New Placement	40
Setting of Placement	40
Permanence of Placement	43
Satisfaction with New Placement	44
Better or Worse than Howe.....	47
Staff Knowledgeable, Skillful, and Supportive Compared to Howe	49
Adequate Supervision	49
Adequate Services.....	50
Social Relationships at New Placement.....	51
Developmental Training Sites.....	53
Visitation.....	54
Visits to Howe.....	54
Visitation to New Placement.....	55
Change in Visitation Frequency.....	55
Travel Time to Howe	57
Change in Travel Time	59
Phase II	60
The Decision to Close Howe	61
Transition Plan.....	61
The Move	61
Relationships.....	62
Quality of Life.....	62
Summary	65
Key Findings.....	66
What are some of the basic trends associated with closure, transition, and placement?.....	66
How satisfied are family/guardians with the closure and its outcomes?.....	66
What were the differences in attitudes towards closure and to community placements between family and state guardians?	66
To what extent did age and level of need affect the type of setting people moved to and family/guardian attitudes to the closure, family placements, and closure's outcomes?.....	67

To what extent did type of setting influence family/guardian attitudes to closure, community placements and closure outcomes? 67

What are the lessons learned regarding family/guardian supports for the transition? 67

Appendix A..... 69

Appendix B 77

References..... 80

INTRODUCTION

The William A. Howe Developmental Center (Howe) was decertified by the Illinois Department of Public Health and its Medicaid contract was terminated by the U.S. Department of Health and Human Services' Centers for Medicare and Medicaid Services (CMS) in April of 2007, resulting from the identification of serious deficiencies by CMS surveyors. The termination of the Medicaid contract resulted in the loss of Medicaid certification and subsequent federal funding of Howe, costing the state at least \$26 million annually (Office of the Governor, 2009). In December of 2007, Howe underwent an investigation by the U.S. Department of Justice (DOJ) pursuant to the Civil Rights of Institutionalized Persons Act (CRIPA), resulting in findings of deficiencies related to transition planning, protection from harm, health care, psychiatric care, behavioral treatments and habilitation, and integrated treatment planning (Department of Justice, 2009). On August 29, 2009, prior to the release of the DOJ report, Governor Pat Quinn announced the closure of Howe.

The August 2009 announcement was the second announcement of the intent to close Howe. The initial announcement occurred on September 5, 2008 with a target closure date of July 1, 2009. On the same day, a notice of intent to close was filed with the Commission on Government Forecasting and Accountability (CGFA) and the Health Facilities Planning Board (DHS, 2008). The CGFA voted 9 to 3 in favor of closure on April 28, 2009 (Office of the Governor, 2009). A month later, Quinn commissioned a report to be completed and recommendations made by an independent consultant. Upon the recommendation of the report authors, Quinn visited Howe in August of 2009. Two weeks later, a press release announced that Howe would be closed by the end of April 2010. At the time of the announcement, Howe had 247 residents and over 700 staff.

Despite opposition by local community leaders, parents, and members of the American federation of State, county and Municipal Employees (AFSCME), Howe closed on June 21, 2010. One hundred and eighty-one individuals moved to seven other State Operated Developmental Centers (SODCs) in Illinois; 45 moved to Community Integrated Living Arrangements (CILAs); and 19 moved to Intermediate Care Facilities for persons with Developmental Disabilities (ICFs/DD). One individual moved to a family CILA and one individual moved out of the state.

Numerous studies have been completed examining deinstitutionalization outcomes for individuals with intellectual and developmental disabilities (I/DD) moving from institutions to community-based settings (see Lakin, Larson, Kim, & Kim, 2011; and Schindler & Rizzolo, 2008). Similar studies have been conducted in Illinois to determine outcomes for individuals leaving 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, 2010). In the spirit of continued monitoring of

outcomes for individuals transitioning out of Illinois SODCs, the Department of Human Services' Division of Developmental Disabilities (DHS-DD) contracted the Institute on Disability and Human Development (IDHD) at the University of Illinois at Chicago (UIC) to conduct an evaluation of stakeholders' experiences of the Howe closure.

METHODS

The primary objective of the present evaluation was to examine stakeholders' experiences with the closure and transition process and the perceived outcomes of the closure as well as the individuals' satisfaction with their current living situation. Information was collected in two phases from both individuals who moved out of Howe as well as from guardians/family members who had a relative/ward living at Howe when closure was announced.

Phase I involved the collection of information from guardians/family members through the use of an anonymous survey. Survey materials were assembled by the research team before being provided to DHS, who then mailed the surveys to the appropriate parties to assure protection of respondent confidentiality. Survey respondents were provided a self-addressed stamped envelope in which to return the completed surveys to UIC for analysis. Survey data was then analyzed using SPSS 16.0.

Information was collected from the following domains (a copy of the survey can be found in Appendix A):

1. Demographics of respondent and/or individual transitioned (age, gender, race/ethnicity, education level)
2. Satisfaction with services at Howe and the decision to close Howe
3. Satisfaction with the transition and closure process
4. Satisfaction with the new placement and the services received there
5. Effects of relocation on visitation patterns
6. Personal opinions of how the relative is doing since transition and the impact closure had on the family.

Phase II involved face to face interviews with individuals who moved out of Howe as a result of its closure. DHS distributed a letter explaining the study to former residents (of which a copy was sent to court appointed guardians when applicable). Interviews, for those who consented to participate, were conducted using an interview guide (which can be found in Appendix B) with questions along five core domains:

1. The decision to close Howe
2. Transition plan
3. The move
4. Relationships
5. Quality of life

Members of the research team met with 15 former Howe residents in the setting of their choice, which was typically their developmental training (DT) program or their current residence. Each participant was given \$20 in cash as compensation for their time. Interviews were recorded (with permission) and later transcribed for analysis.

FINDINGS FROM FAMILY/GUARDIAN SURVEY

Two hundred and forty-four surveys were mailed to family members and guardians. One hundred and three were returned to UIC, a response rate of 42%.

RESPONDENT DEMOGRAPHICS

Relationship Type

A third (33%) of respondents identified themselves as the sibling of the person transitioned out of Howe (Table 1). An additional 31% reported being a parent, 3% an aunt or uncle, 2% a cousin, and 1% a niece or nephew. Three percent reported being a friend of the former Howe resident. The remaining 27% identified themselves as public guardians¹.

Age of Respondent

Almost half of the respondents were between the ages of 60 and 74 years (47%); 37% were under 60 and the remaining 16% were 75 and over (Table 1). Fourteen individuals left this question blank, resulting in a total of 89 responses.

Respondent Gender

About two-thirds of the respondents were female (66%), while 34% were male (Table 1). While state guardians showed a nearly even gender distribution (55% male and 46% female), family guardians were much more often female (73%). This percentage increases to 80% for aging family members (aged 60 and older).

Respondent Race

Most respondents reported their race as White (71%) or Black (25%), while around 4% reported their race as either American Indian/Alaskan Native, "Two or more races," or "Other" (Table 1).

Respondent Ethnicity

Only one respondent reported his/her ethnicity as Hispanic. However, 27 respondents elected not to answer this question.

¹ Since responses were anonymous, it is possible that a state guardian may have returned more than one survey, depending on the number of individuals that guardian was assigned.

Respondent Education

Over one-third of respondents (34%) reported a high school education or less; 18% reported having some college or an Associate’s degree; 24% had a Bachelor’s degree; 17% had a Master’s degree; and 3% had a Doctorate degree (Table 1). Another 3% reported “Other” as their educational category.

Table 1
Respondent Demographics

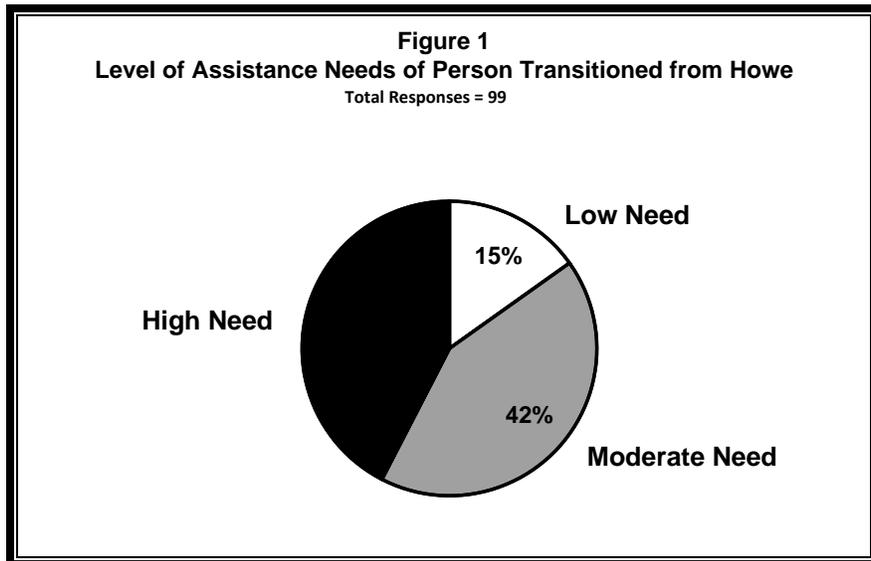
Relationship to Individual at Howe (n= 103)		%
	Parent	31%
	Brother/Sister	33%
	Aunt/Uncle	3%
	Friend	3%
	Cousin	2%
	Niece/Nephew	1%
	Public Guardian	27%
Age (n=89)		%
	Under 60	37%
	60-74	47%
	75 and over	16%
Gender (n=95)		%
	Male	34%
	Female	66%
Race (n=93)		%
	White	71%
	Black	25%
	American Indian/Alaskan Native	1%
	Two or More Races	1%
	Other	2%
Education (n=93)		%
	Less than High School	5%
	High School/GED	29%
	Some College/Associate's Degree	18%
	Bachelor's	24%
	Master's	17%
	Doctorate	3%
	Other	3%

Relative Age

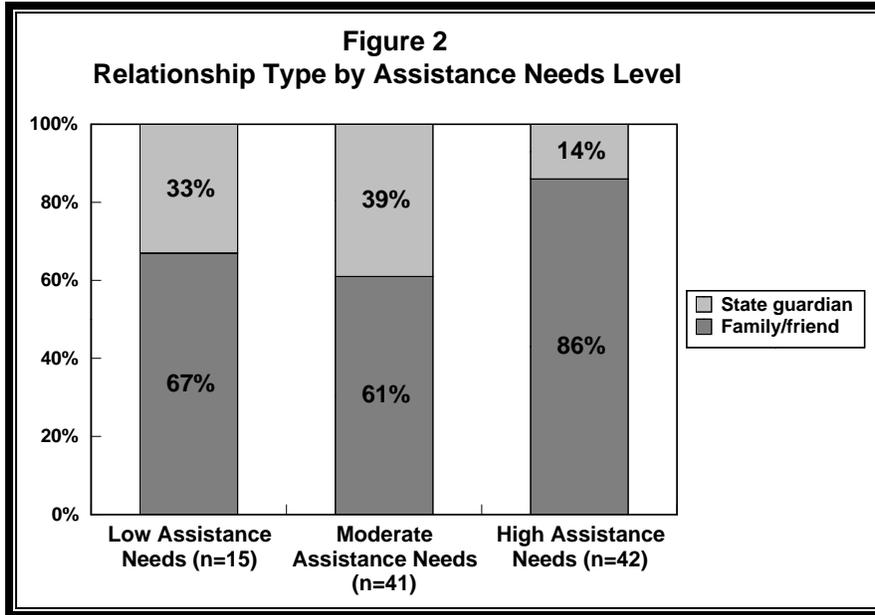
Respondents were asked the age of their relative/ward that transitioned out of Howe. Almost a third (28%) were reported to be under the age of 50, nearly half (50%) between 50 and 74, and 22% 75 and older.

Assistance Needs

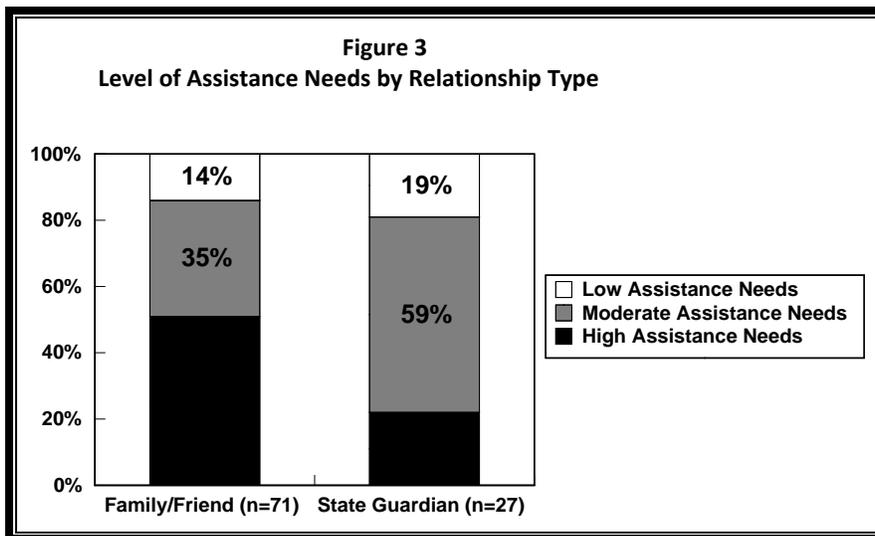
Respondents were given a list of 15 activities, and were asked to mark all activities with which their relative/ward required assistance. These activities included: bathing, dressing, transferring, toileting, eating, walking, going outside, preparing meals, shopping, managing money, using the phone, doing heavy housework, doing light housework, getting outside to places, and managing medications. These were added together and separated into low-, moderate- and high- level assistance needs. Those with 1-7 assistance needs were coded as “low-needs” and represented 15% of responses; those with 8-11 assistance needs were coded as “moderate-needs” and represented 42% of responses; and those with 12 or more assistance needs were coded as high-needs” and represented 42% of the responses. See Figure 1.



Those residents transitioning from Howe who were reported to have high levels of assistance needs were more often represented by family or friends (86%) than state guardians (14%). This difference is significant at the .05 level ($p = .036$) (Figure 2).

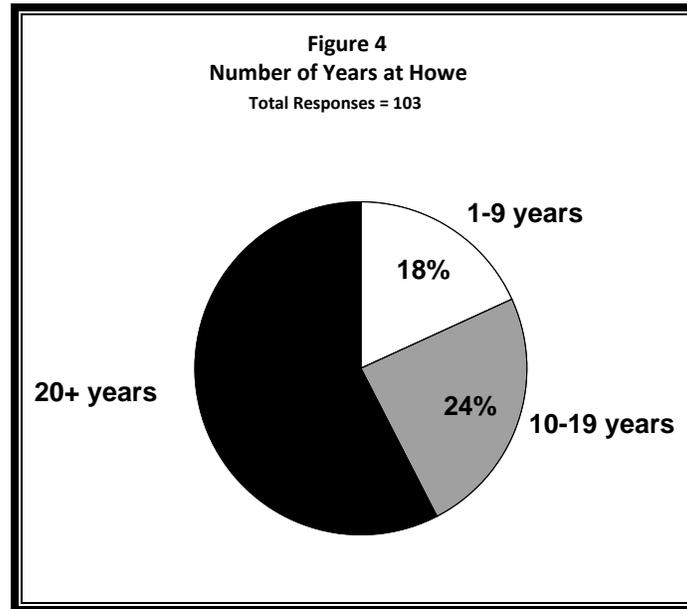


A higher percentage of family/friends reported a high level of assistance needs for their relatives than did state guardians (51% compared to 22%). State guardians more often reported moderate assistance needs (59% vs. 35% of family respondents). These differences are significant at the .05 level ($p = .036$). See Figure 3.



Number of Years at Howe

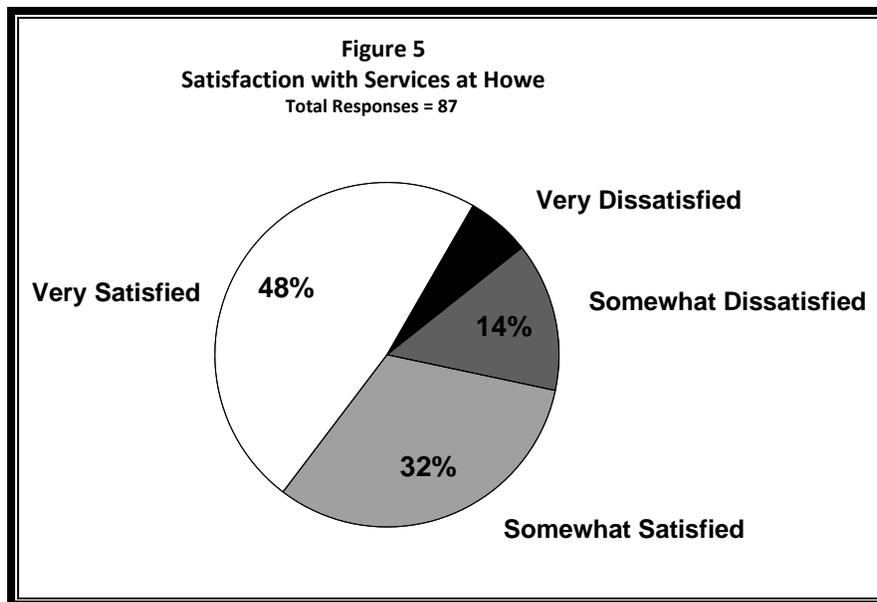
Respondents were asked how many years their relative/ward lived at Howe. A total of 18% of respondents reported that their relative/ward lived at Howe for 1-9 years; 24 % lived there 10-19 years; and 58% had lived there for 20 or more years. See Figure 4.



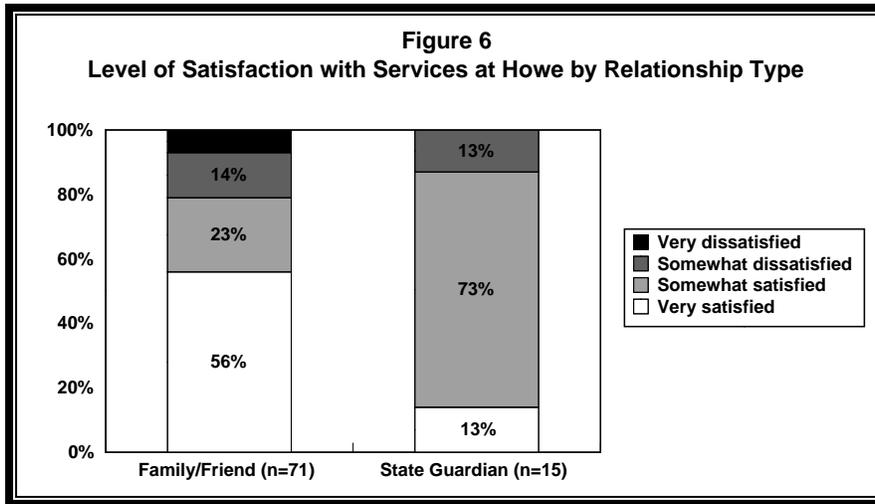
HOWE AND THE DECISION TO CLOSE

Satisfaction with Services at Howe

Respondents were asked to describe the level of satisfaction they had with the services their relative/ward received at Howe, using a scale of 1 (very dissatisfied) to 4 (very satisfied). The average score on this item was 3.23 (SD=.898), indicating that the average respondent was satisfied with the services at Howe. Forty-eight percent indicated they were very satisfied with services at Howe; 32% were somewhat satisfied; 14% reported being somewhat dissatisfied with services at Howe, while 6% reported being very dissatisfied. Eight public guardians left this question blank, as they were not assigned to the individual until after the transition out of Howe. See Figure 5.



Approximately 79% of family members and 86% of state guardians reported being satisfied with services at Howe (Figure 6). Family members, however, were more likely than state guardians to report being “very satisfied” (56% vs. 13%). Fourteen percent of family members and 13% of state guardians reported being somewhat dissatisfied with services at Howe. Seven percent of family members reported being very dissatisfied with services at Howe. No state guardians reported being “very dissatisfied” with Howe. These differences were significant at the .001 level ($p = .001$).



Among family/friends, parents more often reported some level of dissatisfaction with services at Howe (35% compared to 15% of siblings). See Figure 7.

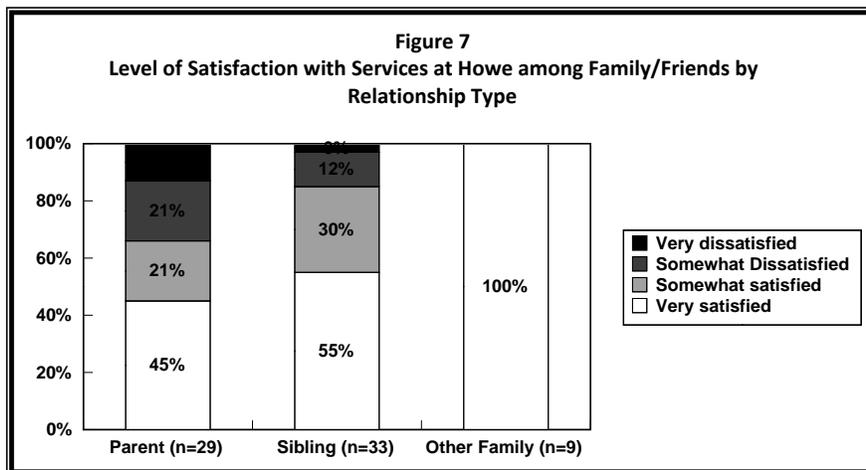
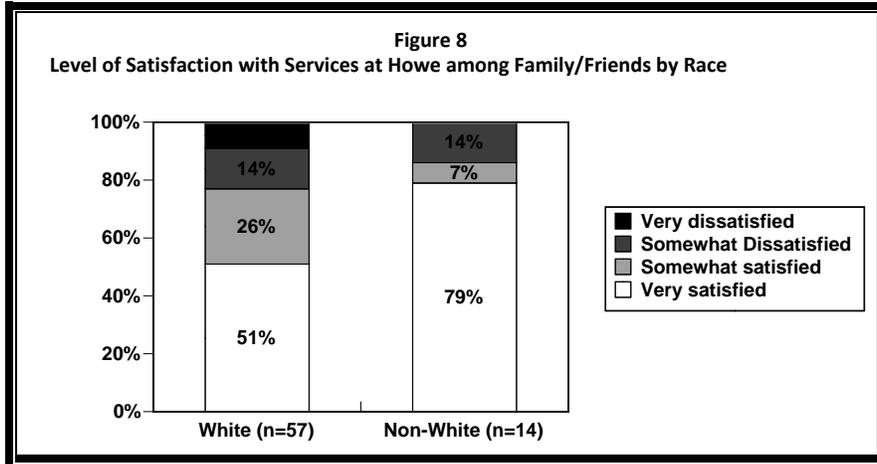


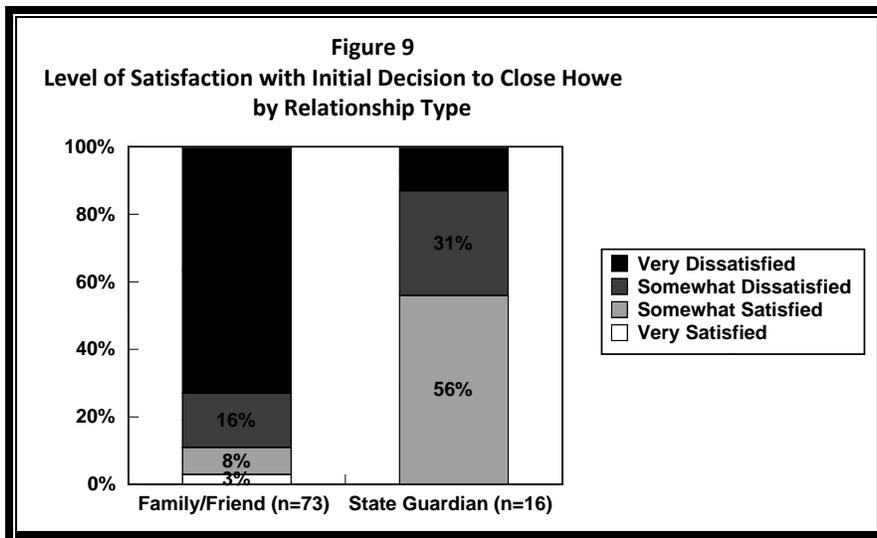
Figure 8 illustrates satisfaction with services at Howe among family members by race.



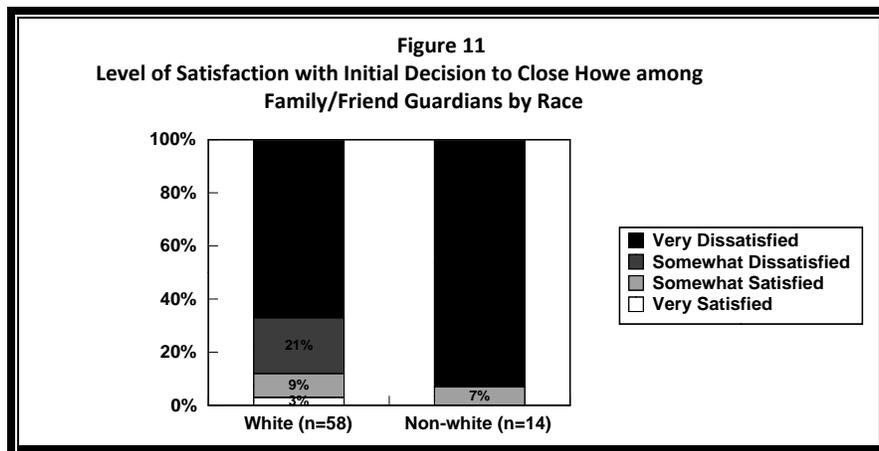
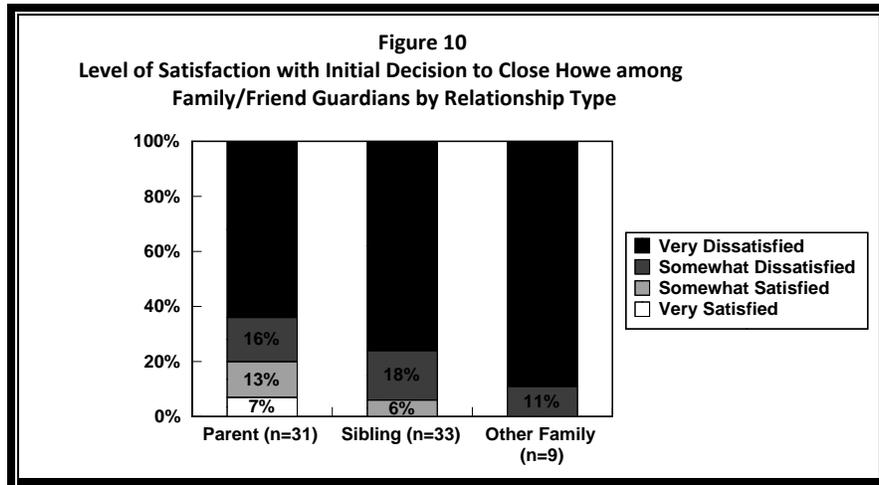
Initial Satisfaction with Howe Closure Decision

Respondents were asked the level of satisfaction they felt when the decision to close Howe was first announced. The four options ranged from “very dissatisfied” (scored as 1) to “very satisfied” (scored as 4). The average score on this item was 1.59 (SD=.847) indicating that the average respondent was “somewhat dissatisfied” with the initial decision to close Howe. Of the 90 responses, most (80%) reported dissatisfaction with this decision.

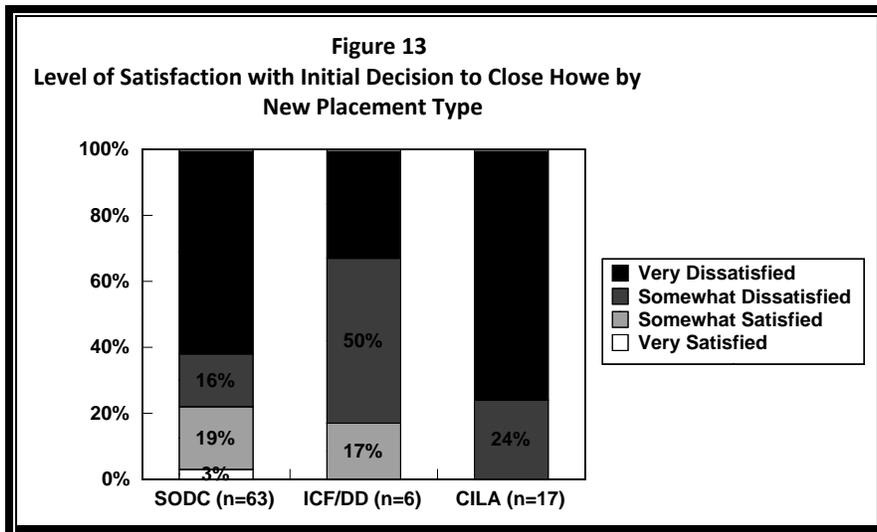
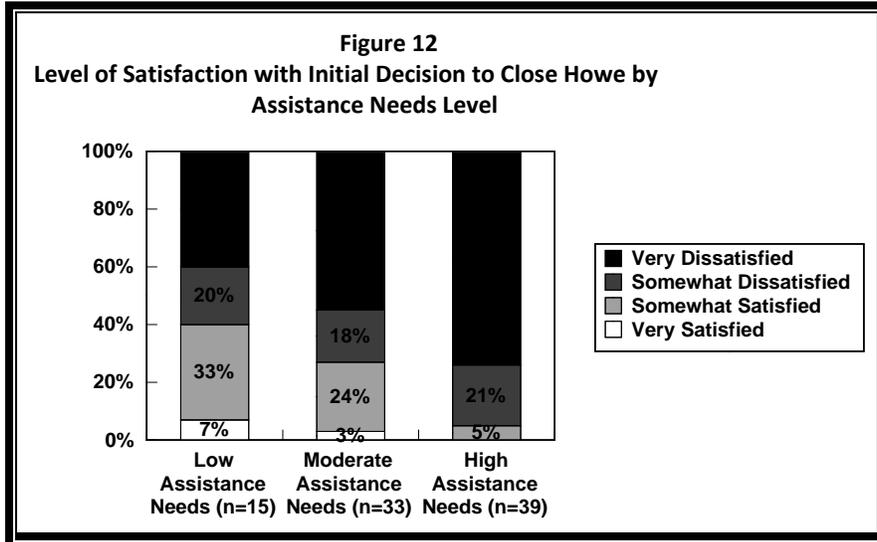
This was especially true for family/friends – 89% of family/friend respondents expressed dissatisfaction with the decision to close Howe versus 44% of state guardians (Figure 9).



The respondents most likely to express dissatisfaction with the decision to close Howe were other family members (aunts, uncles, cousins, nieces, nephews – 89% of this group reported being "very dissatisfied." Seventy six percent of siblings and 64% of parents indicated they were "very dissatisfied" with the decision to close Howe (Figure 10). Non-white family/friends more often reported being very dissatisfied with the initial decision than white respondents (93% compared to 67%). These differences were not statistically significant for this sample See Figure 11.

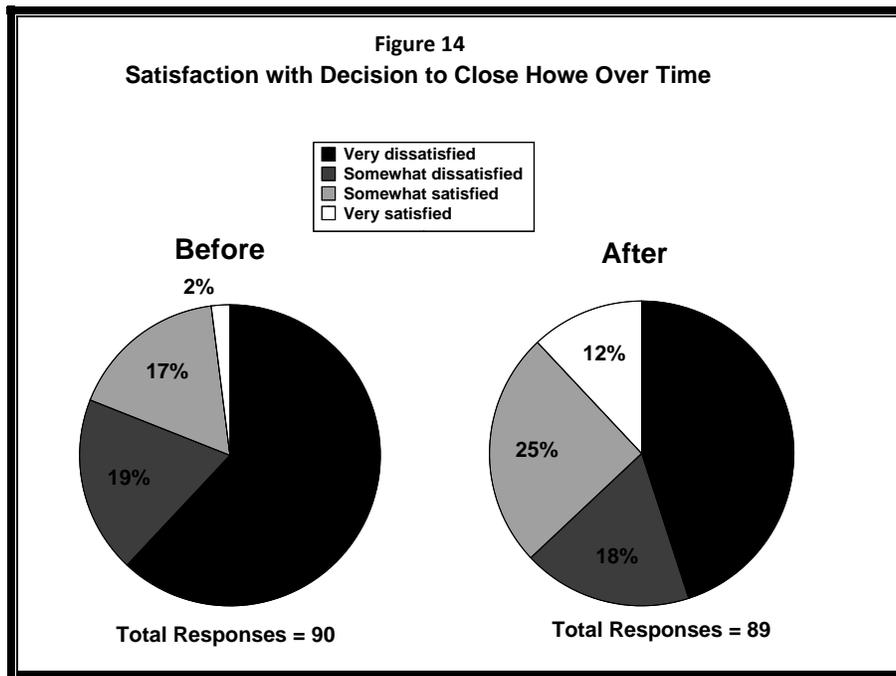


Among all respondents, higher levels of assistance needs were associated with increased levels of dissatisfaction with the initial decision to close Howe. These differences were significant at the .1 level ($p = .081$) (Figure 12). Of those reporting a move to a CILA, none reported being satisfied with the initial decision to close Howe (Figure 13).



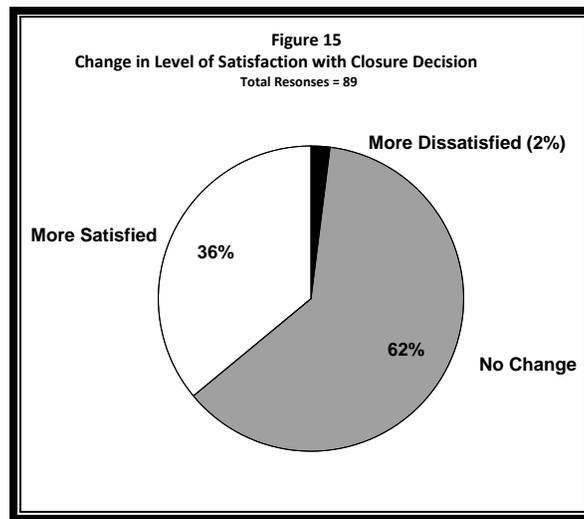
Current Satisfaction with Decision to Close Howe

Respondents were also asked their current level of satisfaction with the decision to close Howe. The four responses ranged from “very dissatisfied” (scored as 1) to “very satisfied” (scored as 4). The average score on this item was 2.04 (SD=1.097), indicating that the average participant was now "somewhat dissatisfied" with the decision to close Howe. The average (2.04) is slightly higher for current satisfaction with the decision than the average for the initial decision (1.58), showing a slight improvement over time in satisfaction with this decision. This change is statistically significant at the .000 level ($p = .000$). See Figure 14.

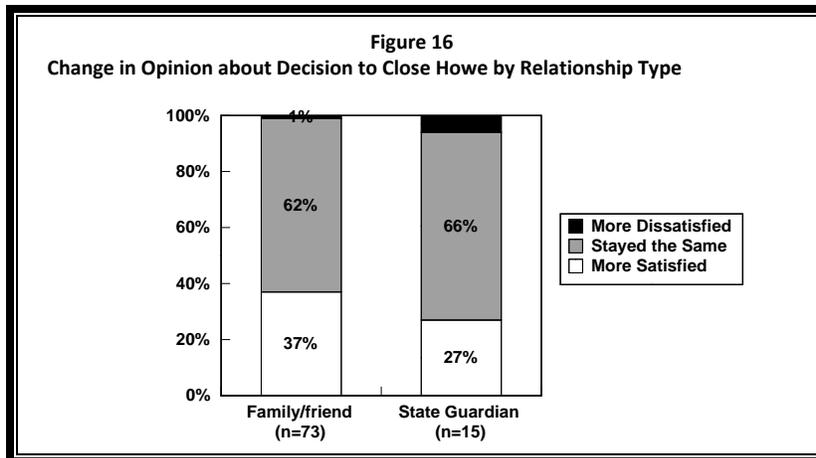


Change in Satisfaction with Decision to Close Howe

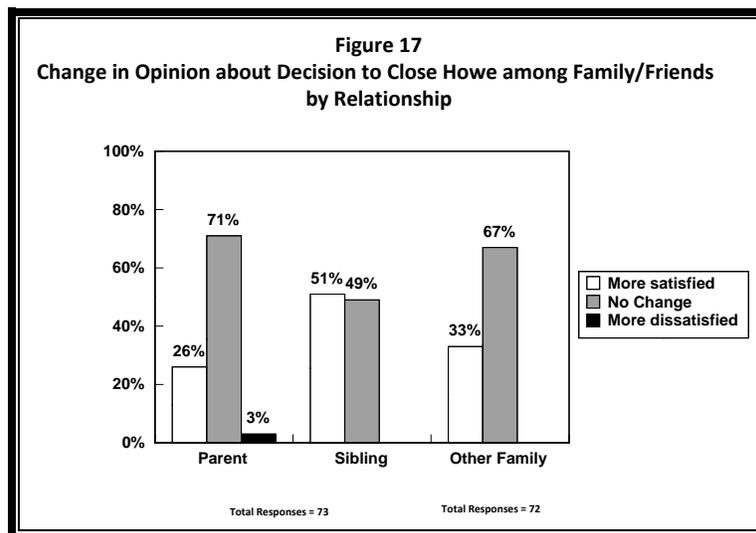
These two items allow us to examine how individual satisfaction has changed since the decision to close Howe. In order to determine this, a new variable was computed which subtracted respondents' initial level of satisfaction from their current level of satisfaction. A score of 0 on this item indicates 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 .46 (SD=.854), meaning that the average respondent felt slightly more positive about the decision over time. The large majority of respondents (62%) scored 0 on this indicating that they had not changed their feelings about the decision to close Howe. A small percentage (2%) now feel more negatively about the decision and 36% now feel more positively about the decision. See Figure 15.



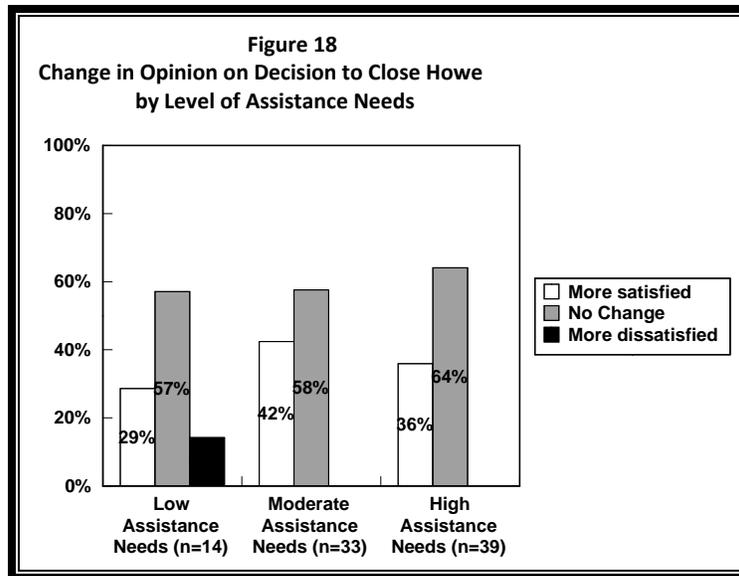
Family/friends more often increased their feelings of satisfaction than state guardians. Thirty-seven percent of family/friends increased their level of satisfaction with the decision, compared to 27% of state guardians. This finding is of interest; however, it does not approach statistical significance with this sample. See Figure 16.



Among family/friends, siblings more often reported a positive change in attitude about the decision (51% vs. 26% of parents and 33% of "other family members" such as aunts, uncles, nieces, nephews, cousins, and friends) while parents' opinions more often stayed the same (71% vs. 67% of other family members and 49% of siblings). See Figure 17. White family/friends more often reported a positive change in attitude towards the closure decision than did non-white family/friends (41% vs. 29%). These differences do not approach statistical significance in this sample.



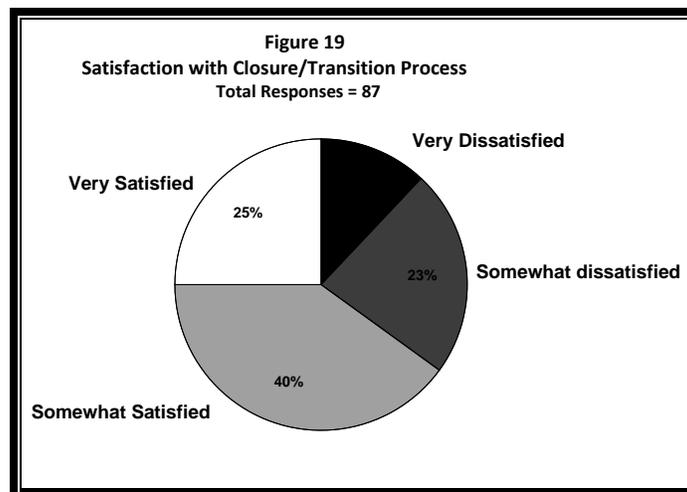
Among all respondents, only those with relatives/wards who have low assistance needs reported currently feeling more negative about the decision to close Howe than they did initially. Fourteen percent of these respondents indicated greater dissatisfaction now than at the initial closure. See Figure 18.



THE CLOSURE PROCESS

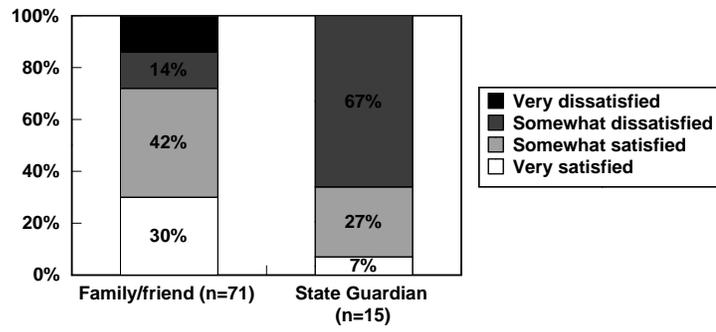
Satisfaction with Closure Process Overall

Respondents were asked to describe their level of satisfaction with the closure/transition process. The four responses ranged from “very dissatisfied” (scored as 1) to “very satisfied” (scored as 4). The average score on this item was 2.79 (SD=.954). A majority (65%) of respondents reported satisfaction with the process. See Figure 19.

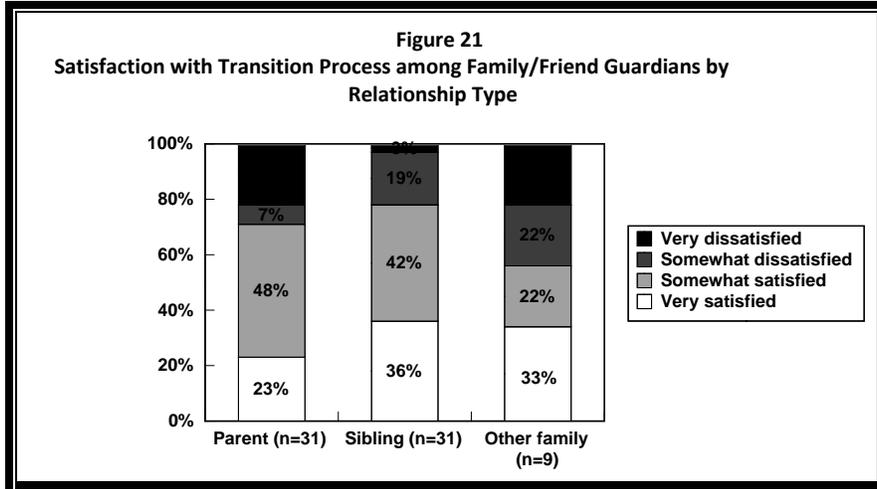


State guardians more often reported being dissatisfied with the transition process than family/friends (67% vs. 28%). These differences are significant at the .000 level ($p = .000$). See Figure 20.

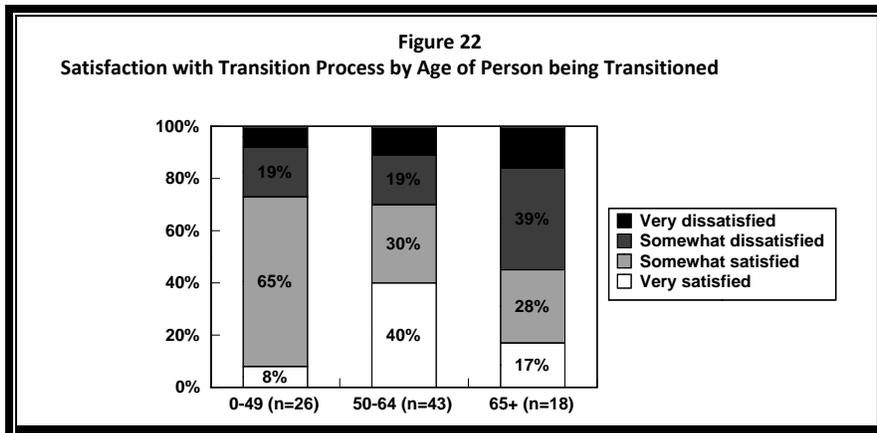
Figure 20
Satisfaction with Transition Process by Relationship Type



Among family/friends, siblings and parents more often reported being satisfied (78% and 71%, respectively) than other family members were (55%). See Figure 21.



Among all respondents, those with relatives/wards between the ages of 50 and 64 more often reported being "very satisfied" with the process of closure (40%), while those with older relatives/wards more often reported some level of dissatisfaction with the process (56% reported dissatisfaction). These differences are significant at the .05 level ($p = .012$). See Figure 22.



Influence Over Transition

Respondents were asked how much they agreed with the following statement: “I had influence over how my relative’s transition out of Howe was carried out.” There were four possible responses ranging from “strongly disagree” (scored as 1) to “strongly agree” (scored as 4). The average score on this item was 3.06 (SD=.859), indicating that the average respondent agreed with this statement. Nearly 87% of state guardians and 81% of family/friends agreed that they had influence, though family members more often "agreed strongly" than did state guardians (37% vs. 7%). These differences were significant at the .05 level ($p = .036$) (Table 2).

My Opinions were Respected

Respondents were also asked their level of agreement with the following statement: “I feel my opinions were respected during the transition process.” There were four possible responses ranging from “strongly disagree” (scored as 1) to “strongly agree” (scored as 4). The average score on this item was 3.21 (SD=.784), meaning that the average participant agreed with this statement. See Table 2.

A little over 70% of state guardians agreed to some degree (7% agreed strongly), and 90% of family/friends agreed to some degree (45% agreed strongly). These differences were significant at the .01 level ($p = .002$). See Table 2. Over 94% of those whose family member moved to a CILA reported that their opinions were respected during transition, compared to 86% of those moving to another SODC and 66% of those moving to an ICF/DD. These differences were significant at the .05 level ($p = .014$).

Table 2
Influence and Respect During the Transition Process

Influence over Transition (n=85)		%
<hr/>		
	<u>Family/Friend (n=70)</u>	
	Strongly Agree	37%
	Somewhat Agree	44%
	Somewhat Disagree	9%
	Strongly Disagree	10%
	<hr/>	
	<u>State Guardian (n=15)</u>	
	Strongly Agree	7%
	Somewhat Agree	80%
	Somewhat Disagree	13%
	Strongly Disagree	0%
<hr/>		
<u>Opinions were Respected</u>		
<hr/>		
	<u>Family/Friend (n=71)</u>	
	Strongly Agree	45%
	Somewhat Agree	45%
	Somewhat Disagree	4%
	Strongly Disagree	6%
	<hr/>	
	<u>State Guardian (n=14)</u>	
	Strongly Agree	7%
	Somewhat Agree	64%
	Somewhat Disagree	29%
	Strongly Disagree	0%
	<hr/>	
	<u>CILA (n=17)</u>	
	Strongly Agree	29%
	Somewhat Agree	65%
	Somewhat Disagree	0%
	Strongly Disagree	6%
	<hr/>	
	<u>ICF/DD (n=6)</u>	
	Strongly Agree	33%
	Somewhat Agree	33%
	Somewhat Disagree	0%
	Strongly Disagree	33%
	<hr/>	
	<u>SODC (n=59)</u>	
	Strongly Agree	42%
	Somewhat Agree	44%
	Somewhat Disagree	12%
	Strongly Disagree	2%

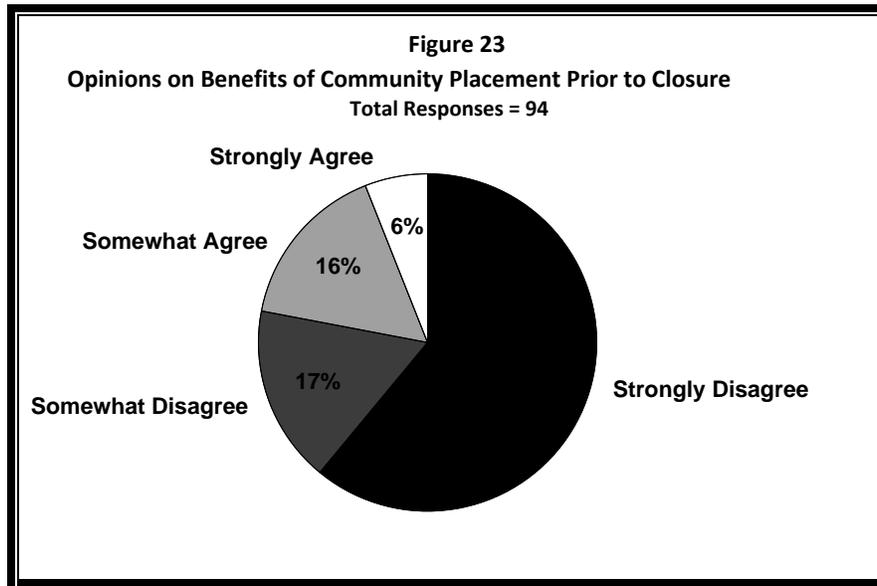
Speed of Closure Process

Respondents were asked how they felt about the speed of closure/transition. Almost half (46%) reported that it moved at a good pace (though only 21% of state guardians felt the pace was good). Another 18% reported that it moved too quickly (over 21% if you limit to family respondents), and 2% that it moved too slowly.

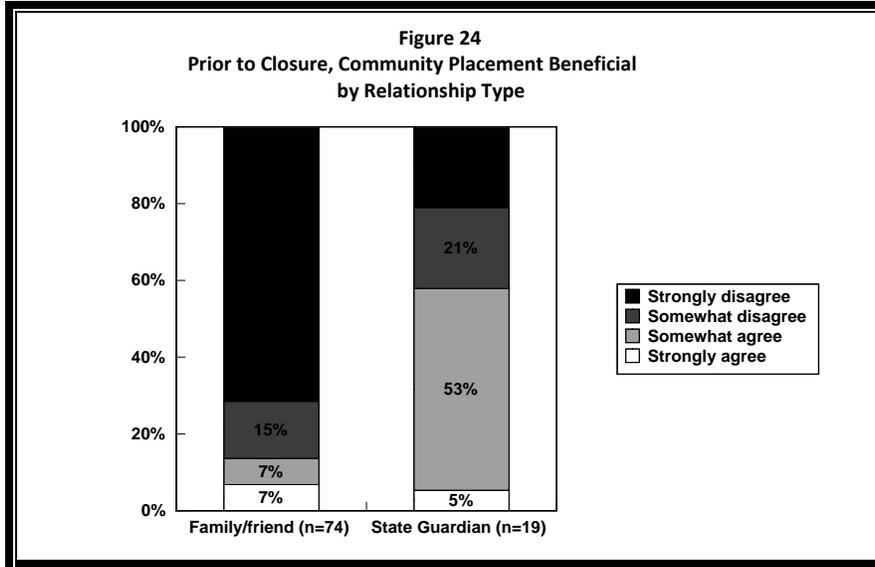
PLACEMENT OPTIONS

Perceived Benefits of Community Placement PRIOR to Closure

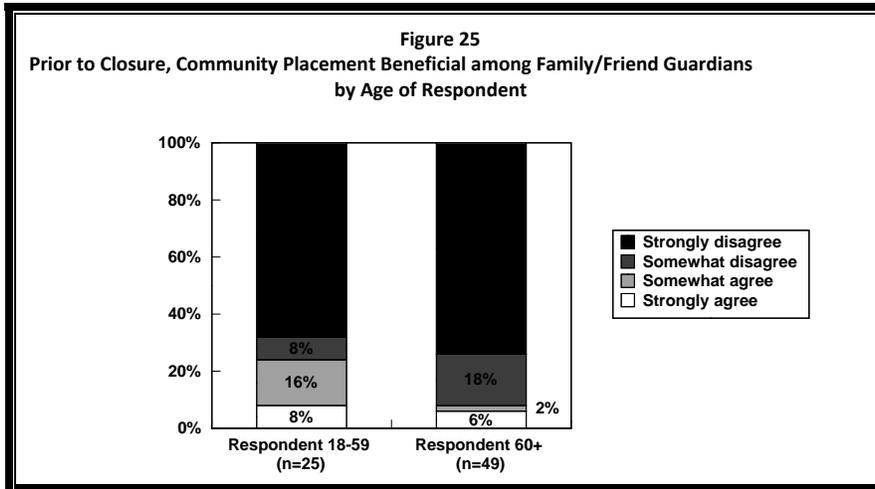
Respondents were asked to describe their level of agreement with the following statement, “Prior to the closure of Howe: My relative would benefit from a move out of an institution and into a community placement.” Responses ranged from “strongly disagree” (scored as 1) to “strongly agree” (scored as 4). The average score on this item was 1.68 (SD=.964), showing that the average participant disagreed with this statement. See Figure 23.



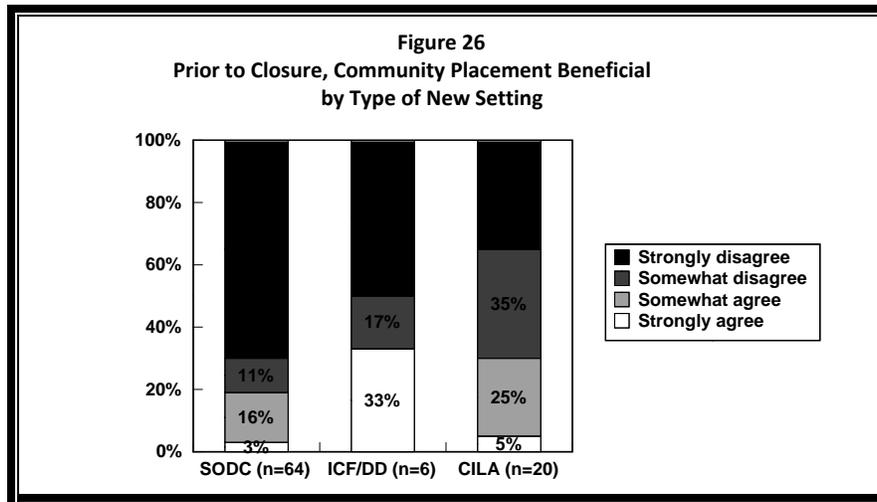
Prior to closure, 58% of state guardians agreed community placement could be beneficial for their ward compared to 14% of family/friends. See Figure 24.



The majority of family/friends over 60 felt that a community placement would not be beneficial for their relative (92% vs. 76% of younger family/friends). See Figure 25.

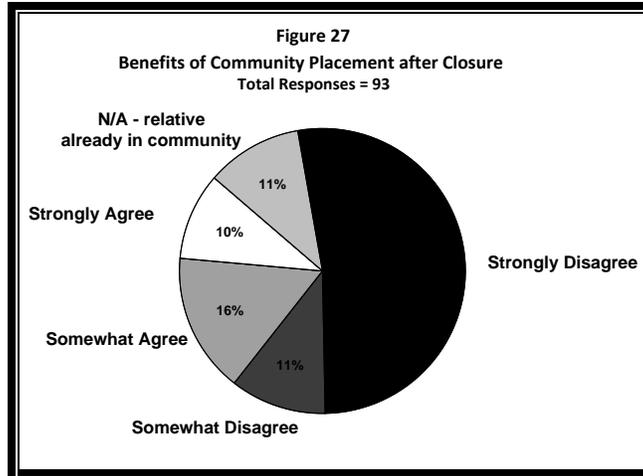


Of those reporting a move to a CILA, 30% reported that, prior to closure, they agreed to some degree that a community placement would be beneficial. A third (33%) of respondents whose relative/ward moved to an ICF/DD reported that, prior to closure, they agreed that their relative/ward would benefit from a community placement (all of them agreed strongly). Conversely, 81% of those reporting a move to an SODC reported disagreeing that community placement could be beneficial (70% disagreed strongly and 11% disagreed somewhat). These differences were significant at the .01 level ($p = .003$). See Figure 26.

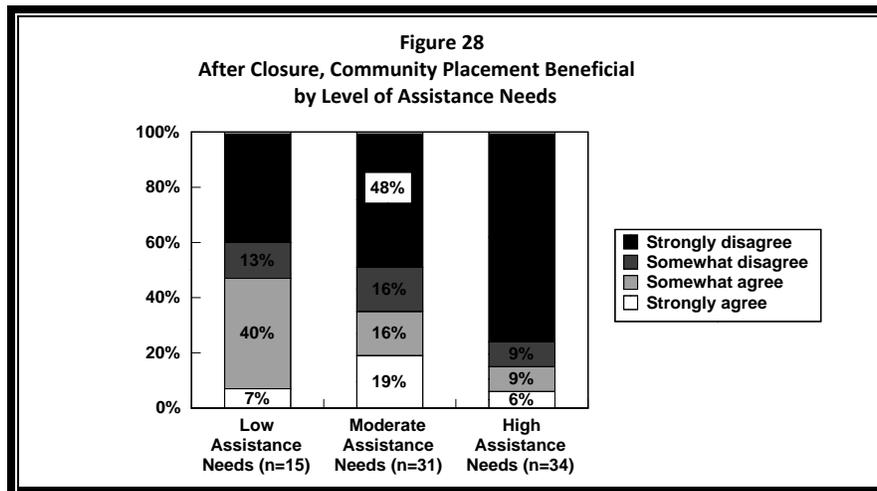


Current Perceived Benefits of Community Placement

Respondents were asked to indicate whether, after the closure of Howe, community placement could be beneficial for their relative/ward. Responses ranged from “strongly disagree” (scored as 1) to “strongly agree” (scored as 4). In addition, they could mark that this was not applicable due to their relative/ward currently being in a community placement. Eleven percent of respondents reported that this was the case. Another 63% indicated disagreeing (either somewhat or strongly) with this statement. The average score on this item was 1.81 (SD= 1.087). This shows that there was a very slight increase (not statistically significant for this sample) in the average respondent’s opinions about the benefits of community placement for their relative/ward after transition out of Howe. See Figure 27.

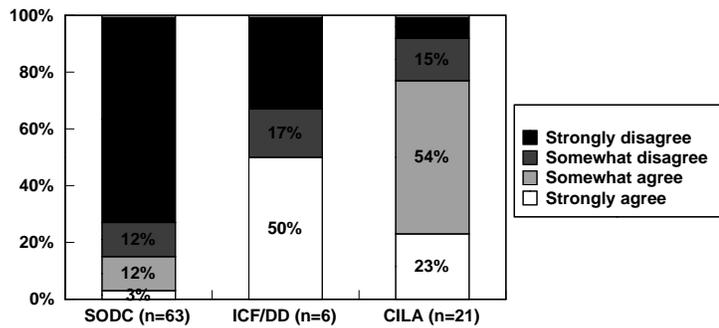


After the closure of Howe, slightly more state guardians reported that they disagreed that a community placement would be beneficial (50%) than had prior to closure (42%). While there were no significant differences on this question prior to closure when looking at different levels of assistance needs, after closure those with relatives/wards with high levels of assistance needs more often reported disagreeing with community placement than the other groups. See Figure 28.



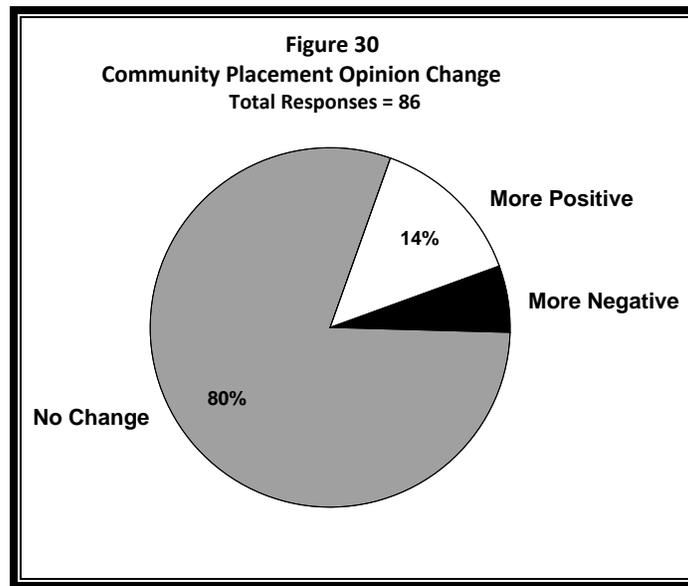
After closure, 77% of those reporting a move to a CILA reported that a community placement would be beneficial compared with 30% who agreed before the move. In contrast, 50% of those reporting a move to an ICF/DD and only 15% of those reporting a move to an SODC reported feeling that a community placement would be beneficial after closure. These differences were significant at the .000 level ($p = .000$). See Figure 29.

Figure 29
After Closure, Community Placement Beneficial
by Placement Type

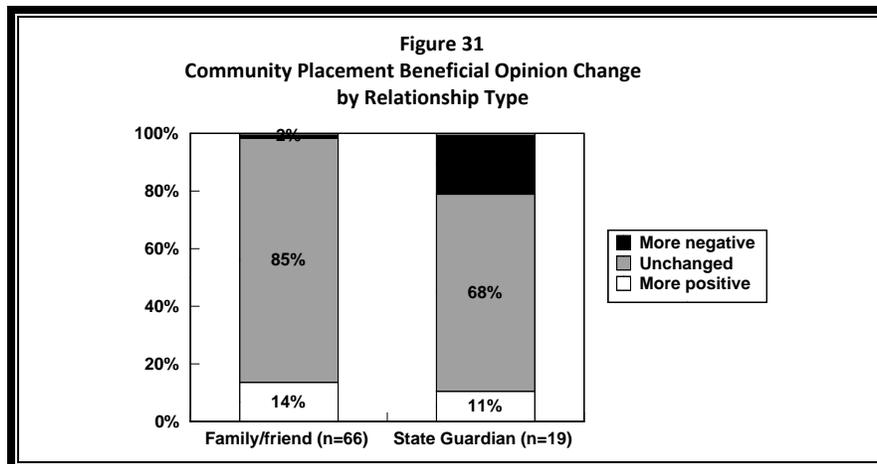


Benefits of Community Placement Change

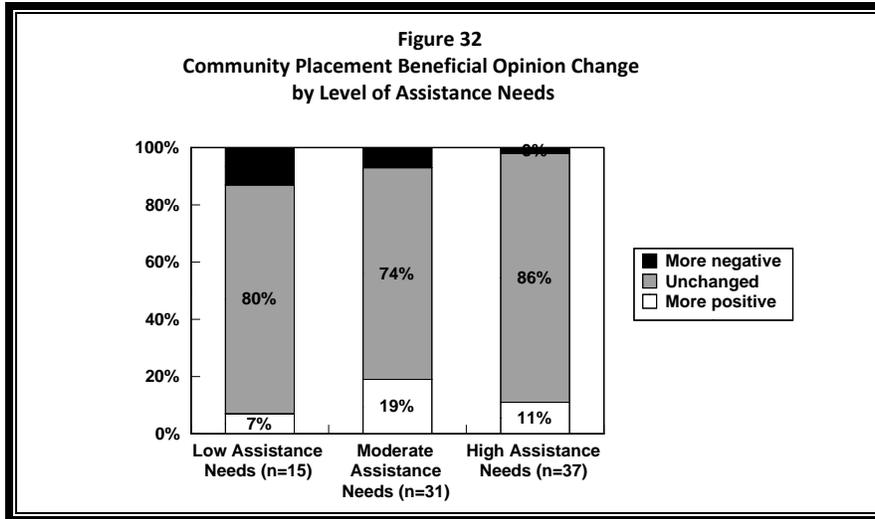
These last two variables allowed for the measurement of the respondent's change in feelings about community placement over time. This variable was constructed by subtracting respondents' scores regarding their previous ideas about community placement from their current ideas about community placement. A negative score on this item indicated more negative feelings about community placement currently, and a positive score indicated more positive feelings about it. A score of 0 indicated no change in opinion. A majority (80%) of respondents' opinions did not change between the time of closure and the survey. Fourteen percent reported more positive opinions, while 6% reported more negative opinions. See Figure 30.



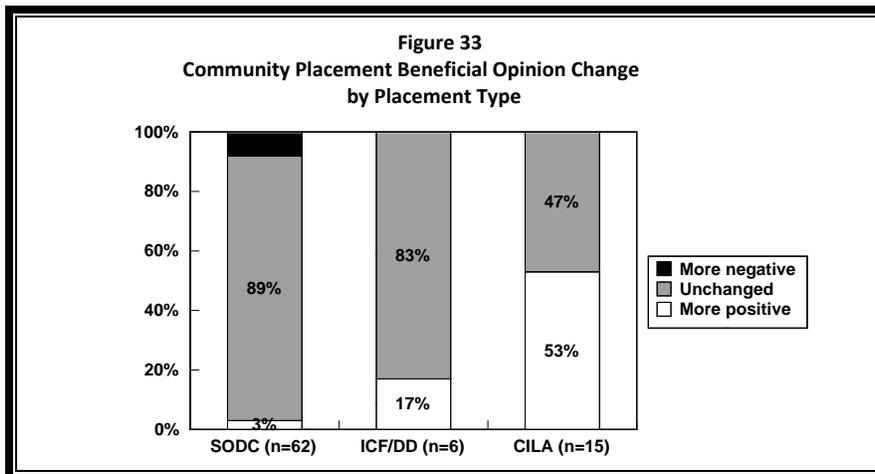
It should be noted that of those who became more negative, only one was a family member and the remainder were state guardians. The opinions of family/friends tended to remain unchanged on this item (85% compared to 68% of state guardians). See Figure 31.



Respondents reporting relatives/wards with moderate assistance needs reported more positive changes in their opinions about the benefits of community placement over time (19%) than did those with either high assistance needs (11%) or low assistance needs (7%). See Figure 32.



Over half of respondents reporting a move to a CILA (53%) reported a positive change in attitude towards community placement compared to 17% reporting a move to an ICF/DD and 3% moving to a SODC. See Figure 33.



Information on Alternative Placements

Respondents were asked whether or not they had received information about other residential options prior to the closure of Howe. Nearly three-quarters (74%) reported that they had.

Respondents were also asked if they had received adequate information on alternative service providers to help them make their decision. Nearly three-quarters (75%) reported that they felt they had received adequate information.

Eighty-one percent of family/friends reported that they had received adequate information on service providers for the decision process compared to 47% of state guardians.

Visiting Placement Options

Participants were asked whether or not they visited the new placement location before making a decision and approximately 75% reported that they had. However, over 30% of respondents over the age of 60 did not visit the new placement prior to transition, compared to 16% of respondents under age 60. Those reporting a move to a CILA more often reported visiting the placement prior to making a decision (95% compared to 67% for ICFs/DD and 70% for SODCs).

Number of Agencies Visited Prior to Transition

Respondents were also asked how many agencies they visited prior to their decision. Over one-third (35%) reported visiting no agencies at all; 41% visited one or two; 19% visited three or four; and 5% visited five or more agencies. The average score for this item was .94 (SD=.889), indicating that the average participant visited 1-2 agencies.

Most of the state guardians (86%) reported visiting zero agencies prior to making a placement decision compared to only 26% of family/friends. These differences were significant at the .01 level ($p = .001$). However, 79% indicated that they had visited the new placement prior to the transition, suggesting that state guardians may have visited these agencies prior to the announced closure of Howe. Among family/friends, only parents reported visiting five or more agencies. Older family/friends were more likely to indicate they did not visit agencies prior to closure than younger family/friends (33% vs. 13%, respectively). However, these differences were not statistically significant for this sample. See Table 3.

Table 3
Number of Agencies Visited Prior to Placement

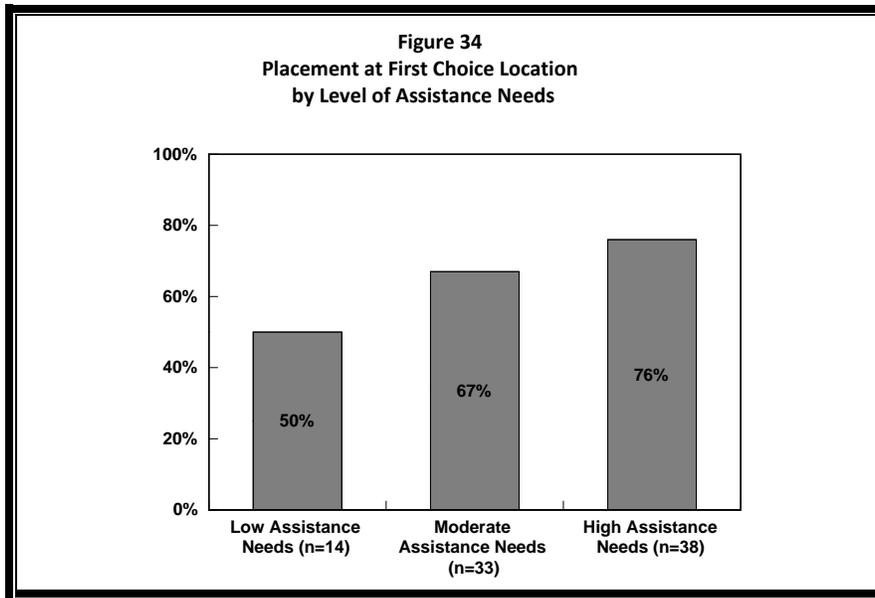
Number of Agencies Visited	%
<hr/>	
Family (n=73)	
	0 26%
	1-2 47%
	3-4 22%
	5+ 5%
<hr/>	
State Guardian (n=14)	
	0 86%
	1-2 7%
	3-4 7%
	5+ 0%
<hr/>	
Parent (n=31)	
	0 23%
	1-2 45%
	3-4 19%
	5+ 13%
<hr/>	
Sibling (n=33)	
	0 27%
	1-2 42%
	3-4 30%
	5+ 0%
<hr/>	
Other Family (n=9)	
	0 33%
	1-2 67%
	3-4 0%
	5+ 0%
<hr/>	
Respondent under 60 (n=27)	
	0 19%
	1-2 56%
	3-4 22%
	5+ 4%
<hr/>	
Respondent 60+ (n=61)	
	0 43%
	1-2 34%
	3-4 18%
	5+ 5%

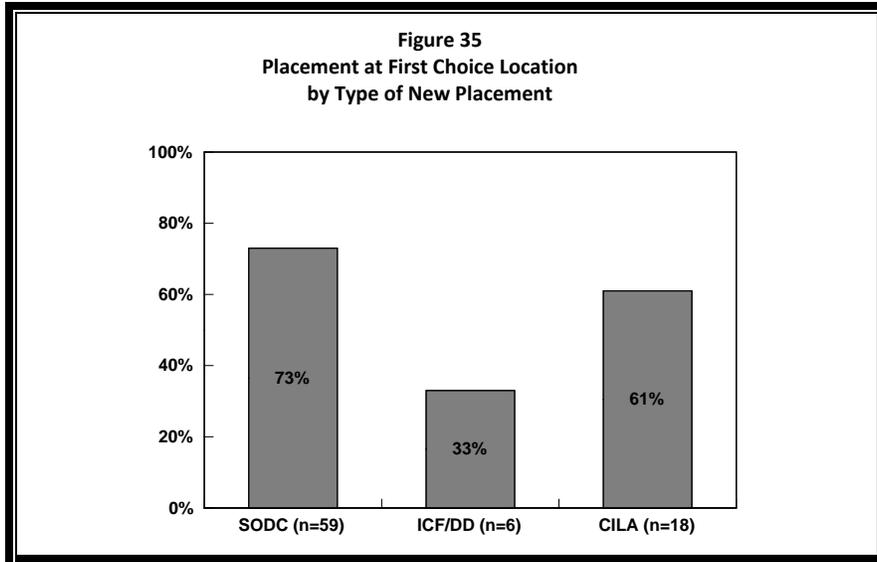
Placement at Preferred Location

Participants were asked whether or not their relative/ward was placed in their first choice of settings. Over two-thirds (69%) reported that their relative/ward was placed in their first choice.

About half (47%) of state guardians reported placement at their first choice of locations compared to 73% of family/friends.

Those with relatives/wards with higher levels of assistance needs more often reported placement at their first choice. See Figure 34. Two-thirds (67%) of those reporting a move to an ICF/DD reported that they did not receive placement at their first choice of settings compared to 39% of those reporting a move to a CILA and 27% of those moving to an SODC. See Figure 35.

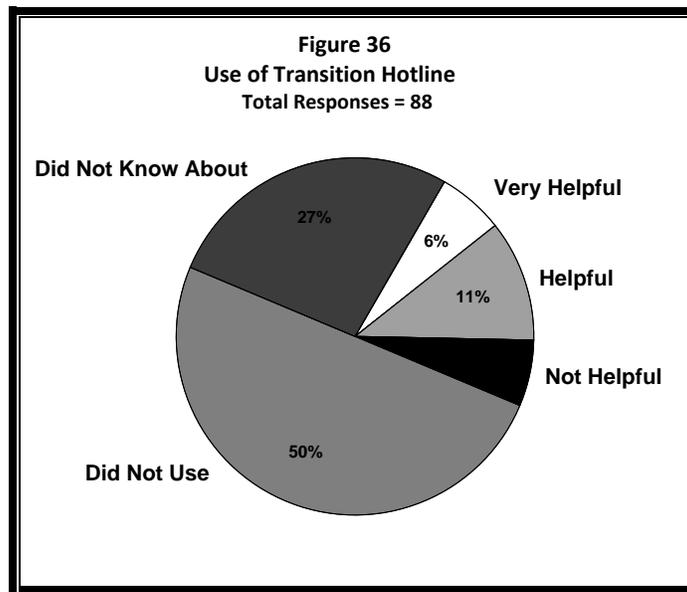




Transition Services

Respondents were asked about their satisfaction with two transition services: the transition hotline and the family liaison. Respondents were given three options “not helpful,” “helpful,” or “very helpful.” In addition, respondents could report that they did not use the service, or they were unaware of the service.

In the case of the transition hotline, only 23% reported using it. Of those who did utilize this service, about 75% found it to be helpful.

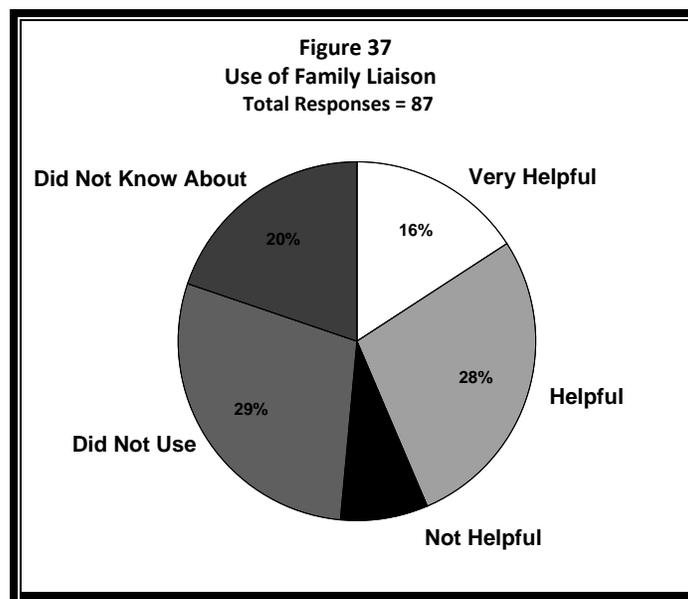


Family/friends were more likely to not know about this service than state guardians (30% vs. 12%). Non-white family/friends more often reported not knowing about this service (50%) than white family/friends (26%).

Almost 60% of older respondents reported not using the transition helpline (57% vs. 37% of younger respondents); while younger respondents more often reported that they were unaware of the hotline (37% vs. 22% of older respondents).

In the case of the family liaison, there were similar findings with 41% reporting either not using the service or being unaware of it. Of those who did use it, 85% (44% of all respondents) reported that it was helpful. See Figure 37.

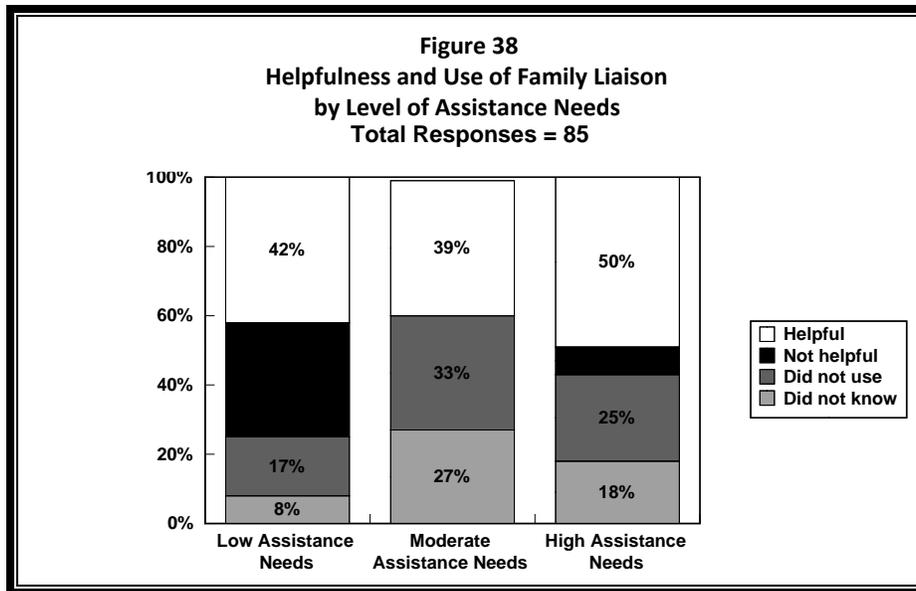
A higher percentage of respondents reported using the family liaison services than the transition hotline. Over half (52%) reported using this service (with 44% reporting that it was helpful). Over one-quarter (29%) reported not using the family liaison service and the remaining 20% reported not knowing about it. See Figure 37.



Older respondents more often reported not using this service (33% vs. 19%), but younger respondents (under age 60) more often reported not knowing about the service (26% vs. 17%).

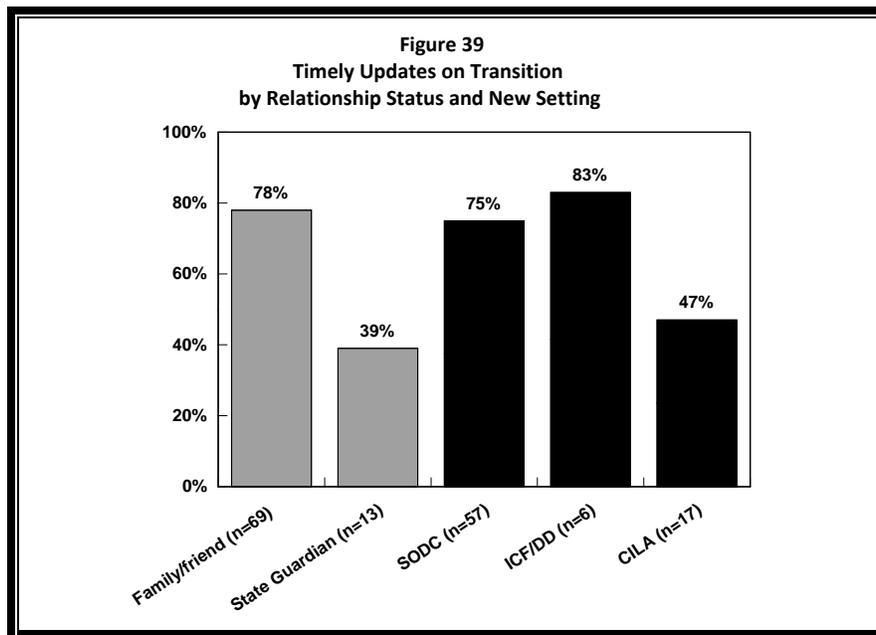
Over 75% of respondents who had relatives/wards with low assistance needs used the family liaison service, compared to 58% of those with relatives with high assistance needs and 40% of those whose relatives had moderate assistance needs.

For families of individuals with low assistance needs who utilized the family liaison, 56% believed it to be helpful, while 44% did not. All the families of individuals with moderate assistance needs that used the service found it helpful, and over 86% of the families of individuals with high assistance needs who used it found it to be helpful. See Figure 38.



Transition Updates

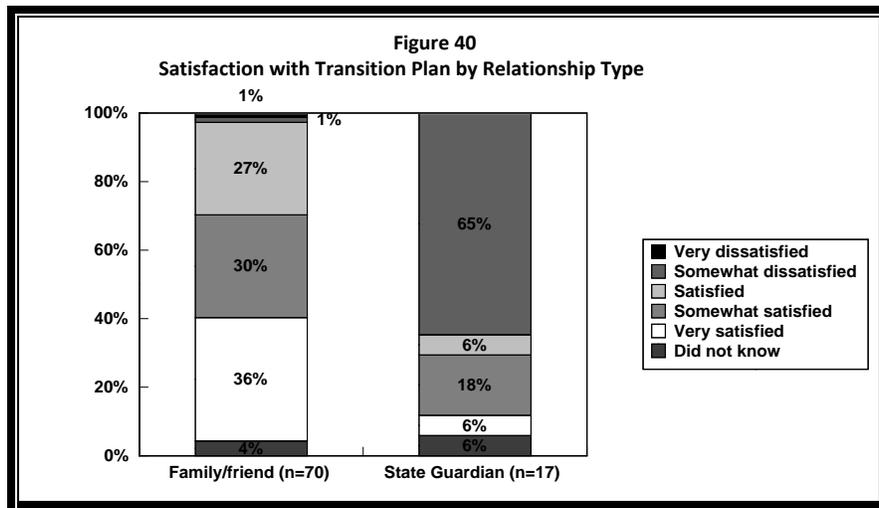
Respondents were also asked whether or not they had received timely updates on their relative’s transition from Howe. On this item, 71% of all respondents reported they had. Family/friends more often reported receiving timely updates about the transition process than state guardians (78% vs. 39%). Those reporting a move to a CILA more often reported they did not receive timely updates on the transition (53% compared to 25% reporting a move to an SODC and 17% reporting a move to an ICF/DD). See Figure 39.



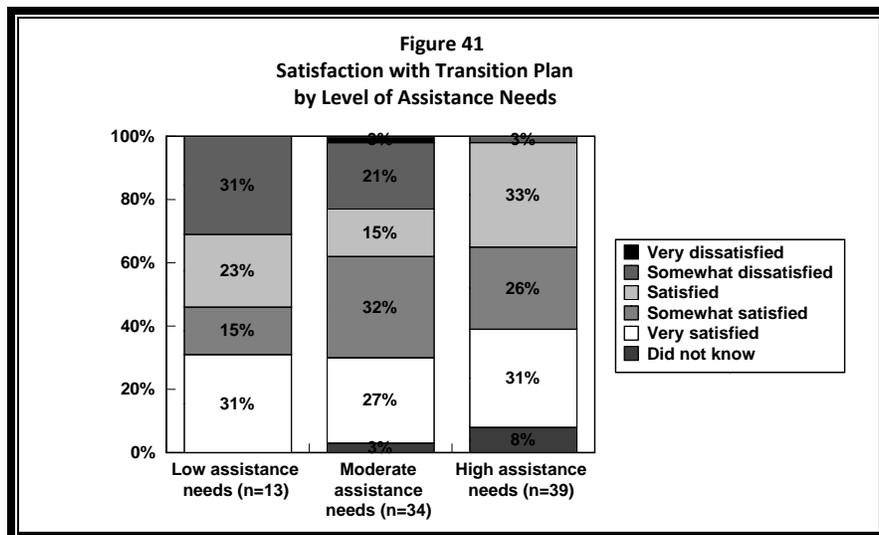
Transition Plans

In addition, respondents were asked about their level of satisfaction with their relative/ward's Transition Plan. They could rank their level of satisfaction from "very dissatisfied" (scored as 1) to "very satisfied" (scored as 5). Over 80% were satisfied with the transition plan. Approximately 15% were dissatisfied with the plan. The average score on this item was 3.74 (SD=1.09) indicating that the average participant was satisfied with the transition plan. Five percent were unaware there was a plan.

State guardians more often reported some level of dissatisfaction with the transition plan than did family/friends (65% vs. 2%). See Figure 40.



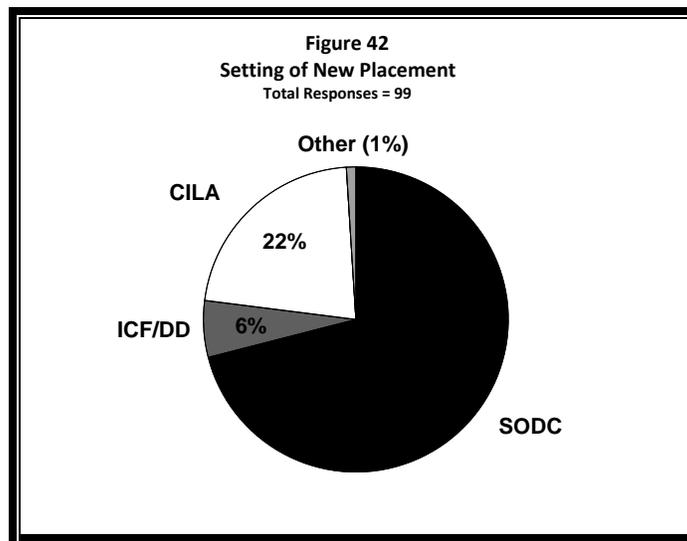
Those respondents with relatives/wards with high assistance needs more often reported being satisfied with the transition plan (91%) than those with low assistance needs (69% satisfied). See Figure 41.



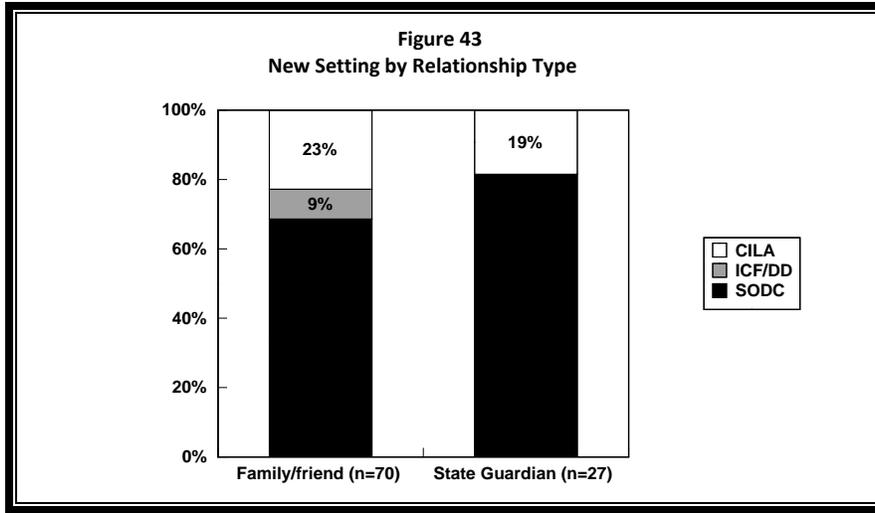
NEW PLACEMENT

Setting of Placement

Respondents were asked about the type of setting to which their relative/ward had been moved: another State Operated Developmental Center (SODC), an Intermediate Care Facility for Persons with Developmental Disabilities (ICF/DD), a Community Integrated Living Arrangement (CILA), and a qualitative “Other” category. On this item, only one respondent reported “Other” as their answer, and added that they were not sure how the new placement would be classified. A majority (71%) reported that the new placement was within an SODC, 22% within a CILA, and 6% within an ICF/DD. See Figure 42.

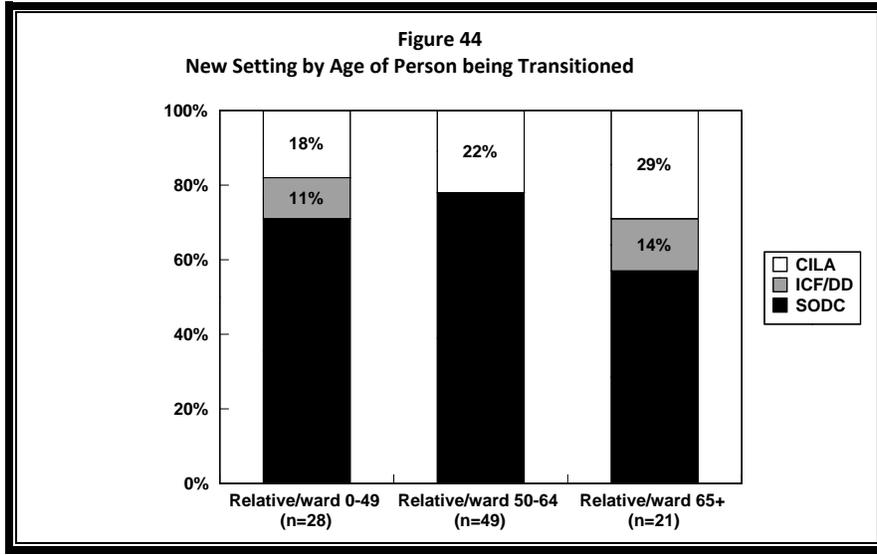


Despite often exhibiting a more positive attitude towards the benefits of community placement, a higher percentage of state guardians reported moves to an SODC than did family/friends (82% vs. 69%). Similar percentages of both groups reported a move to a CILA (19% of state guardians and 23% of family/friend respondents). However, family/friends more often reported a move to an ICF/DD (9% compared to 0 state guardian wards). These differences did not approach statistical significance for this sample. See Figure 43.

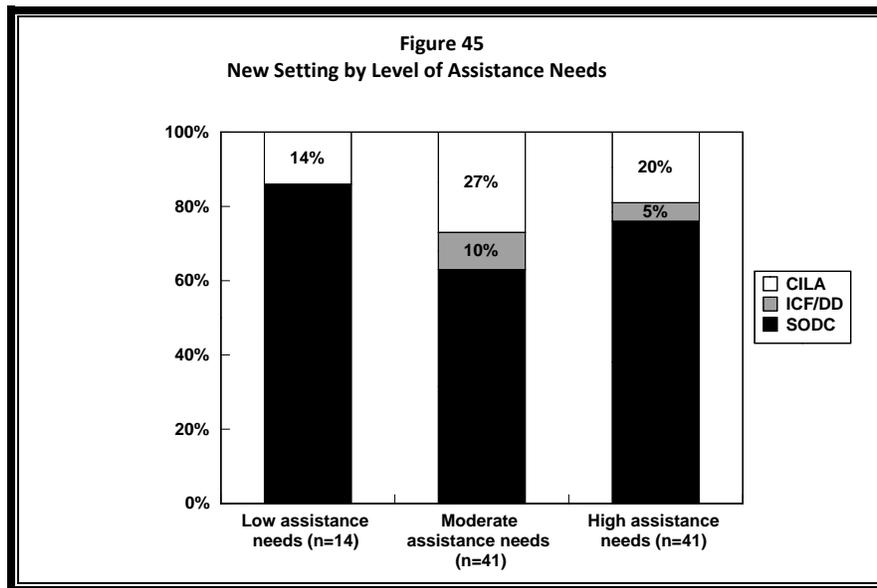


Among family/friends, “other family members,” or those who were neither parent nor sibling, more often reported moves to another SODC (89% compared to 62% of siblings and 67% of parents).

State-operated Developmental Centers (SODCs) were the primary placement type for all age groups. Seventy-one percent of individuals below age 50, 78% of those 50-64, and 57% of individuals aged 65+ moved to other SODCs. Conversely, older individuals were more likely to move to CILAs (29% of this group) than individuals aged 50-64 (22%) or younger individuals under age 50 (18%). See Figure 44.



SODCs were also the primary placement type regardless of level of assistance needs. Eighty six percent of individuals with "low assistance needs" were transitioned to SODCs. Sixty three percent of individuals with "moderate assistance needs" and 75% of individuals with "high assistance needs" were transitioned to other SODCs after leaving Howe. No individuals with low assistance needs were moved to ICFs/DD, but 10% of those with moderate assistance needs and 5% of those with high assistance needs were transitioned to these settings. Finally, 14% of those with low assistance needs, 27% of those with moderate needs and 20% of those with high assistance needs moved to community integrated living arrangements (CILAs). See Figure 45.



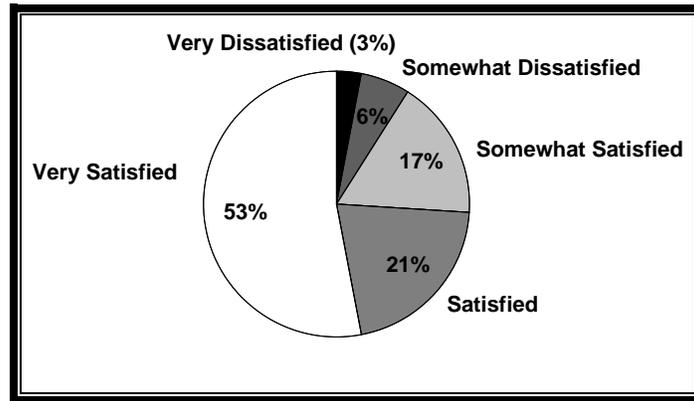
Permanence of Placement

When asked whether or not the new placement would be temporary or permanent, most (80%) reported it was permanent, while 7% reported that it was temporary, and 13% reported they were uncertain.

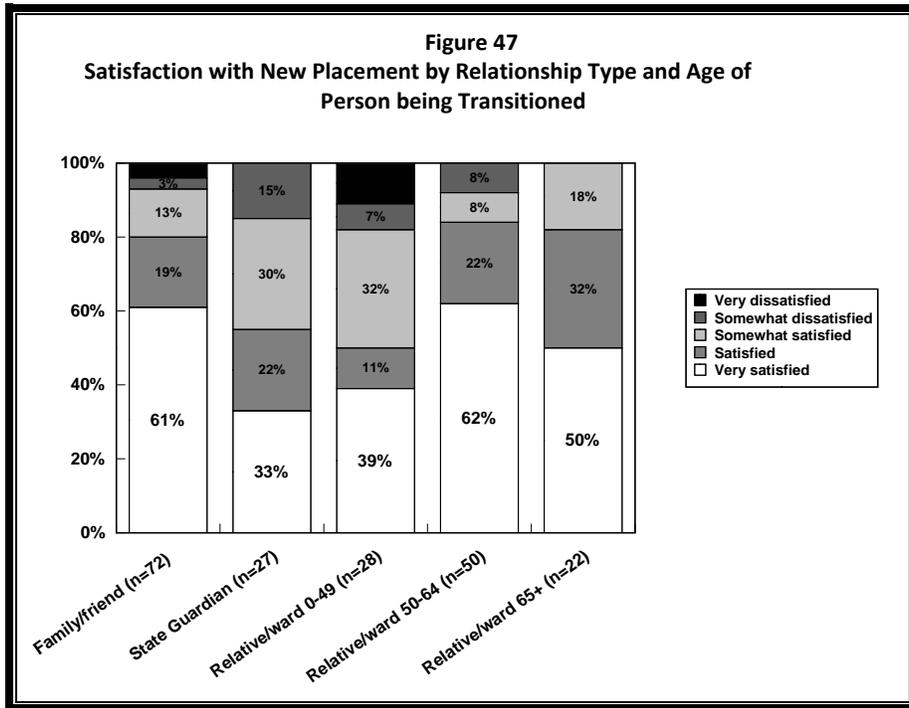
State guardians more often reported a temporary move (15% vs. 4%) or uncertainty regarding the permanence of the placement (19% vs. 11%) than family/friends. These differences were significant at the .1 level ($p = .099$).

Satisfaction with New Placement

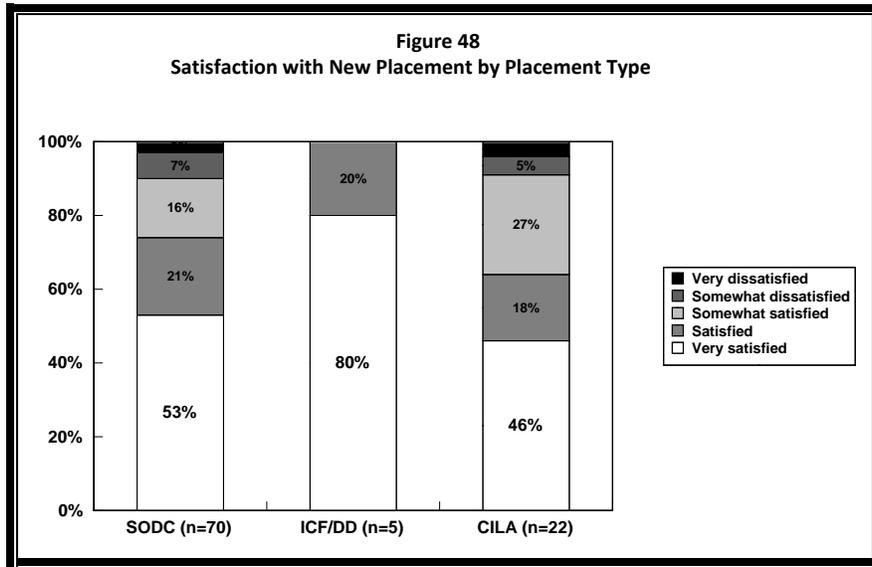
Respondents were asked a series of questions about their satisfaction with the new placement. First they were asked how satisfied they were with the living situation overall. Respondents were given five options ranging from “very dissatisfied” (scored as 1) to “very satisfied” (scored as 5). Most (91%) reported some level of satisfaction (with over half (53%) reporting being "very satisfied"). Nine percent of respondents reported some level of dissatisfaction with the new placement. The average score for this item was 4.11 (SD=1.118), indicating that the average respondent was satisfied with the new living situation. See Figure 46.



Ninety-three percent of family/friends reported satisfaction with the current living situation compared to 85% of state guardians. These differences are significant at the .05 level ($p = .017$). See Figure 47. Satisfaction also varied slightly (though not at a statistically significant level) by age of respondent – all respondents over age 65 reported being satisfied with the new placement compared to 92% of respondents aged 50-64 and 82% of respondents under age 50.

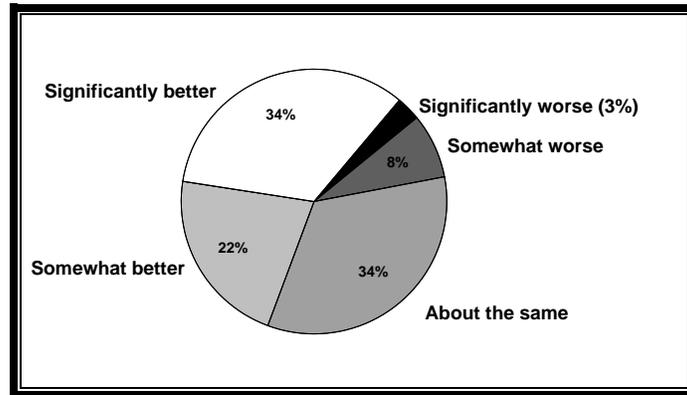


Satisfaction was high across placement settings. One hundred percent of respondents whose relative moved to an ICF/DD expressed satisfaction with the new placement. Ninety percent of respondents whose relatives moved to both SODCs and CILAs were satisfied with the new setting, while 10% of respondents whose relatives moved to SODCs or CILAs were not satisfied (Figure 48).

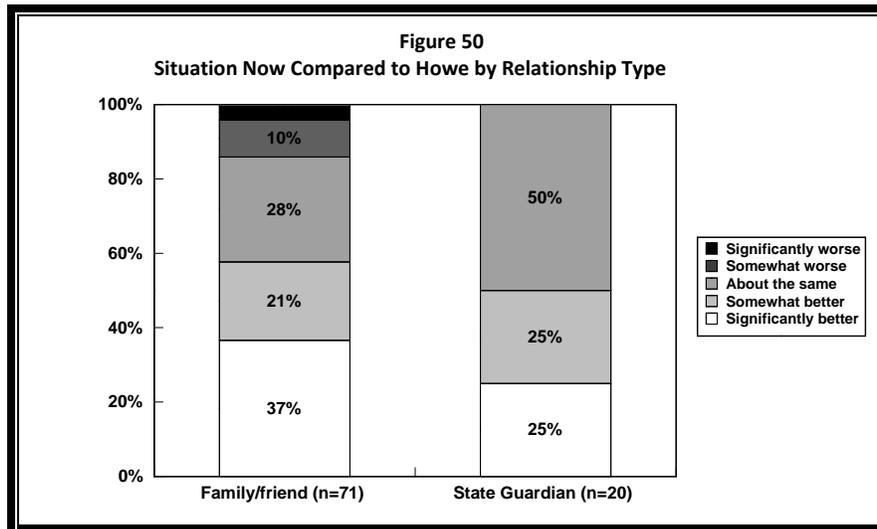


Better or Worse than Howe

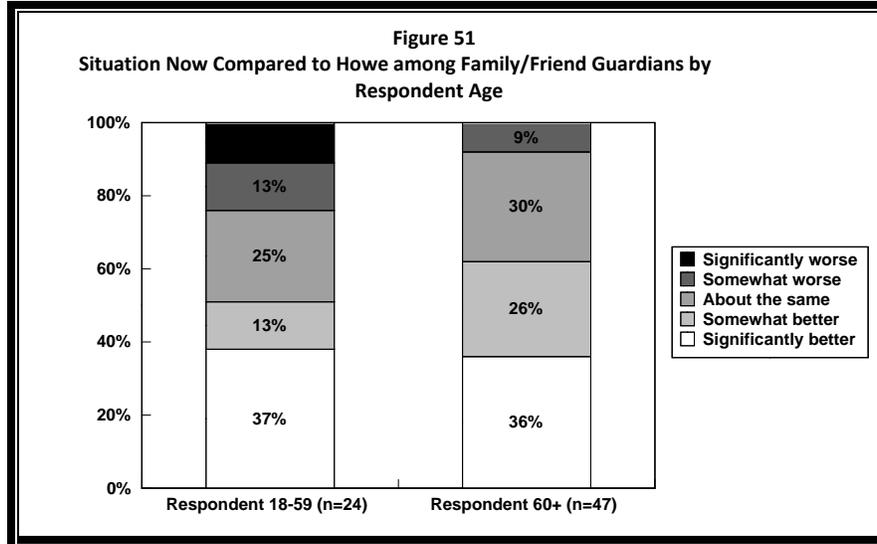
Participants were asked if their relative was better or worse off now than at Howe. A third, (34%) of respondents felt their family member was significantly better than at Howe, 22% somewhat better, and 34% about the same. Approximately 11% reported that their relative/ward was in a worse condition. See Figure 49.



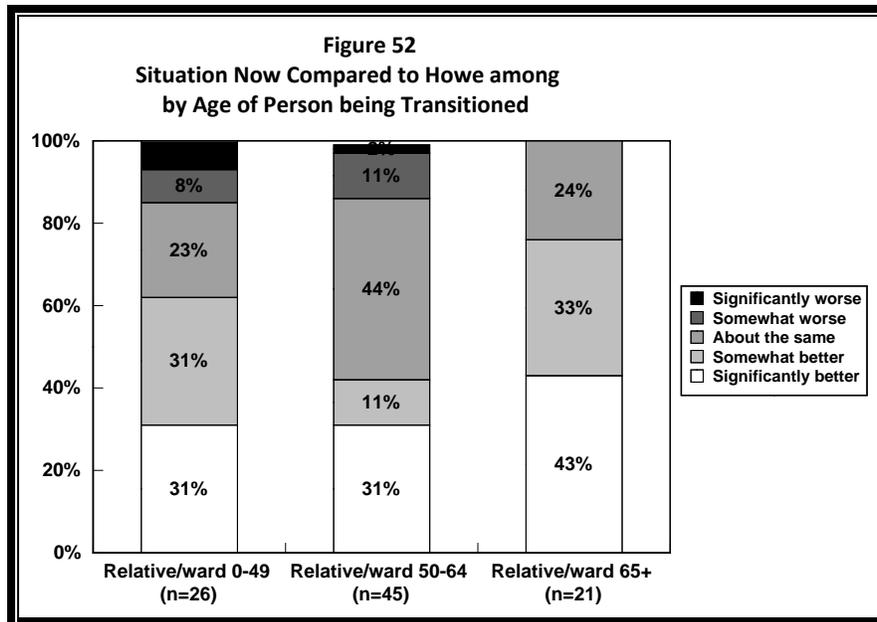
No state guardians reported that their ward was in a worse condition now than prior to moving from Howe, though 14% of family/friends did so. The majority (50%) of state guardians reported that their wards were about the same, compared to 28% of family/friends. See Figure 50.



Younger family/friends more often reported that their relative was worse off now than at Howe (25%) versus older family/friends (8%). See Figure 51.



Responses varied based on the age of the individual that transitioned from Howe. All respondents of individuals aged 65+ felt their family member was doing better (76%) or the same (24%). For individuals aged 50-64, respondents felt 42% of them were doing better, 44% the same, and 11% worse. For individuals under the age of 50, respondents felt 60% were better off, 23% the same, and 16% worse. See Figure 52.



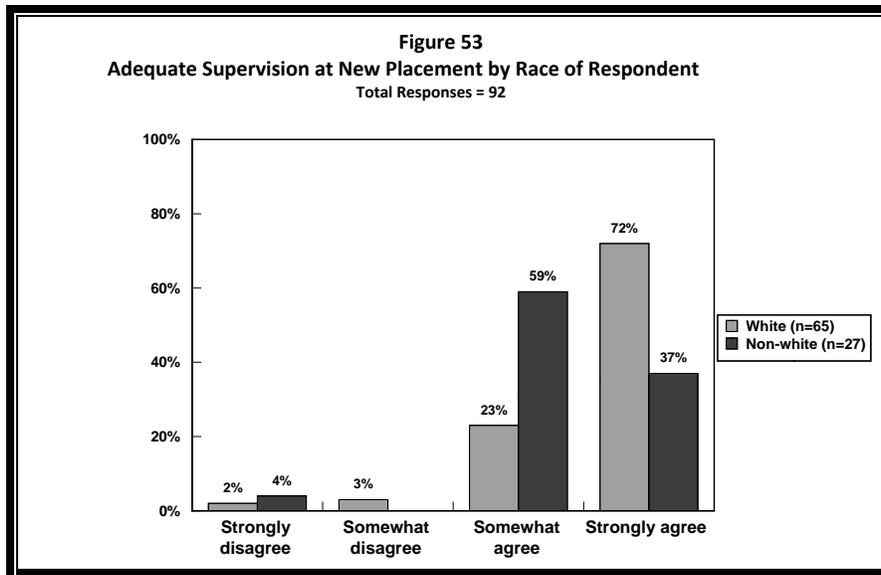
Staff Knowledgeable, Skillful, and Supportive Compared to Howe

The participants were also asked whether or not the staff members at the new placement were as knowledgeable, skillful, and supportive as the staff at Howe. Respondents were given four options ranging from “strongly disagree” (scored as 1) to “strongly agree” (scored as 4). A small percentage (10%) disagreed. Around 90% agreed (46% strongly agreed) that the staff members were as knowledgeable, skillful, and supportive. The average score for this item was 3.33 (SD=.750), meaning that the average participant agreed with this statement.

Adequate Supervision

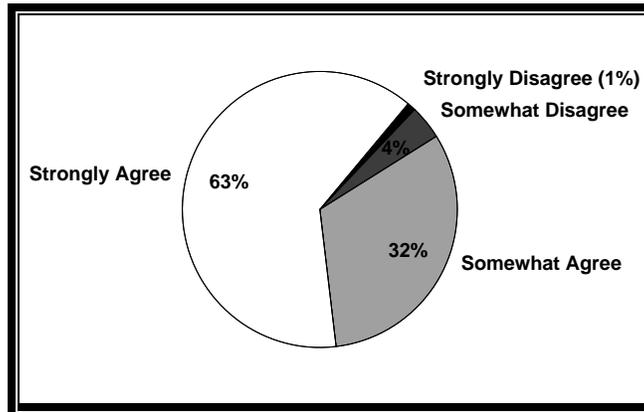
Respondents were asked whether or not their relative received adequate supervision at his/her new home. Respondents were given four options ranging from “strongly disagree” (scored as 1) to “strongly agree” (scored as 4). The majority (94%) agreed to some degree (62% strongly and 32% somewhat agreed).

There were no statistical differences on this measure between state guardians and family/friends. While similar percentages of both white and non-white respondents reported some level of agreement that supervision is adequate at the new placement, white respondents did so more strongly than non-white participants. These differences are significant at the .01 level (p = .006). See Figure 53.

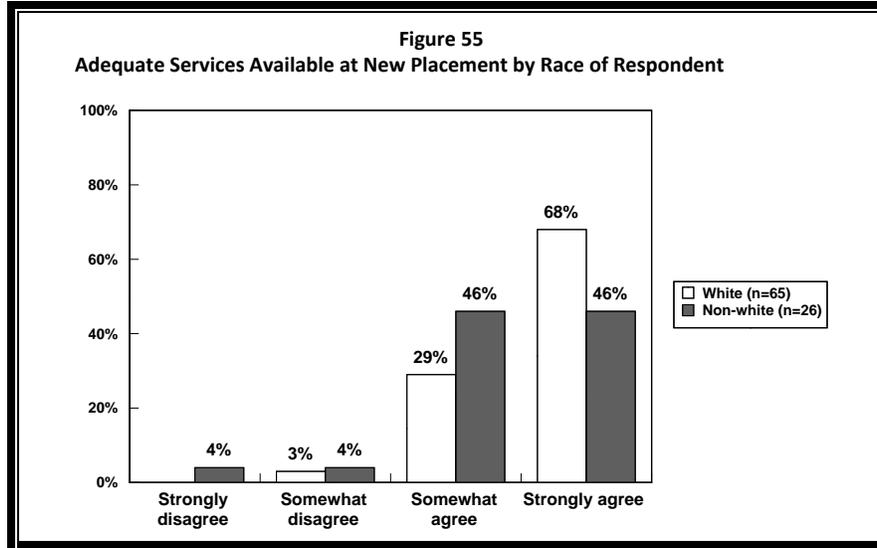


Adequate Services

Respondents were asked whether necessary services were available to their relative in the new home. Again, a large majority (95%) agreed they were. Five percent felt services were not available. The average score for this was 3.54 (SD=.671). See Figure 54.

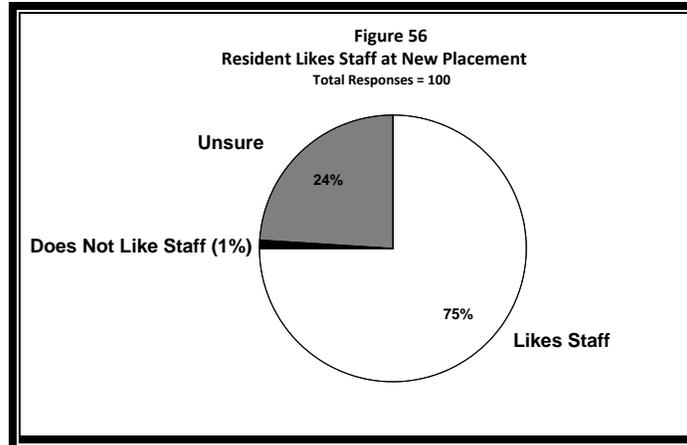


There were no statistical differences on this measure between state guardians and family/friends. White participants showed stronger agreement with the availability of adequate services than non-white participants. See Figure 55.

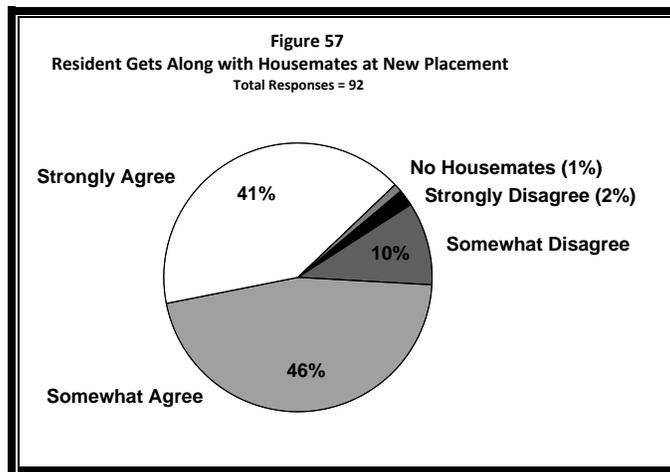


Social Relationships at New Placement

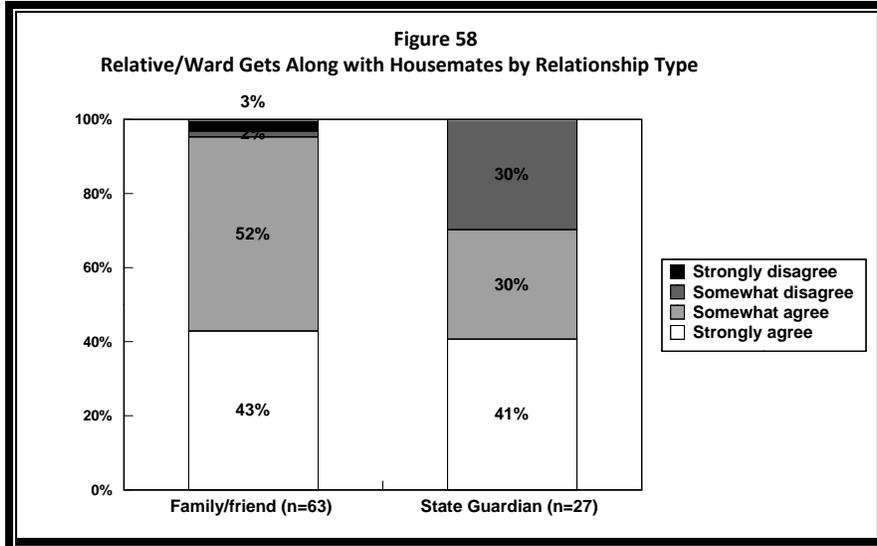
Respondents were asked about social relationships at the new placement. First, respondents were asked how their relative/ward felt about the staff at the new placement. Three-quarters reported that their relative/ward liked the staff. Another 24% reported that they were not sure. When state guardians were asked this same question, over 1/3 (35%) reported that they did not know (compared to 19% of family/friends). See Figure 56.



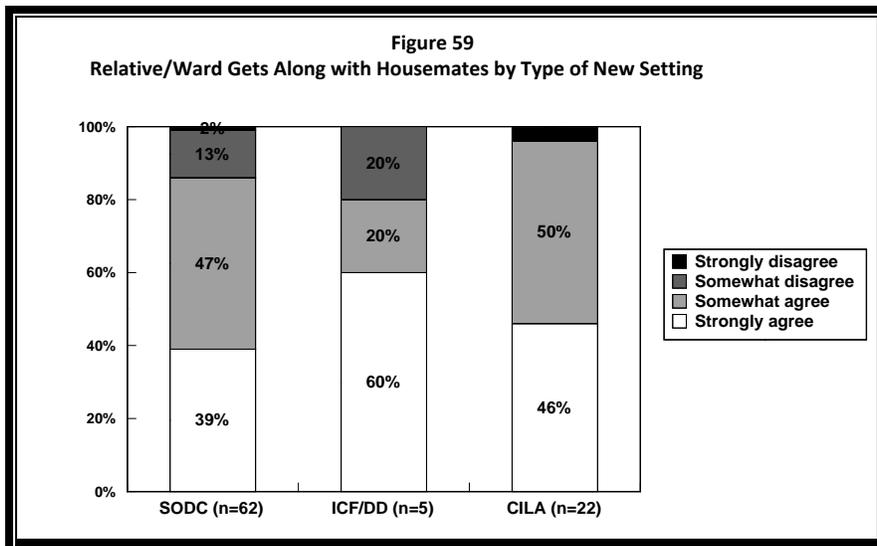
Respondents were also asked to indicate their level of agreement with the following statement: “My relative gets along with his/her new housemates.” A majority (87%) agreed with that statement, 12% disagreed, and 1% did not have housemates. The average score on this item was 3.27 (SD=.731). See Figure 57.



Almost 30% of state guardians disagreed that their ward gets along with new housemates (compared to 5% of family/friends). See Figure 58.



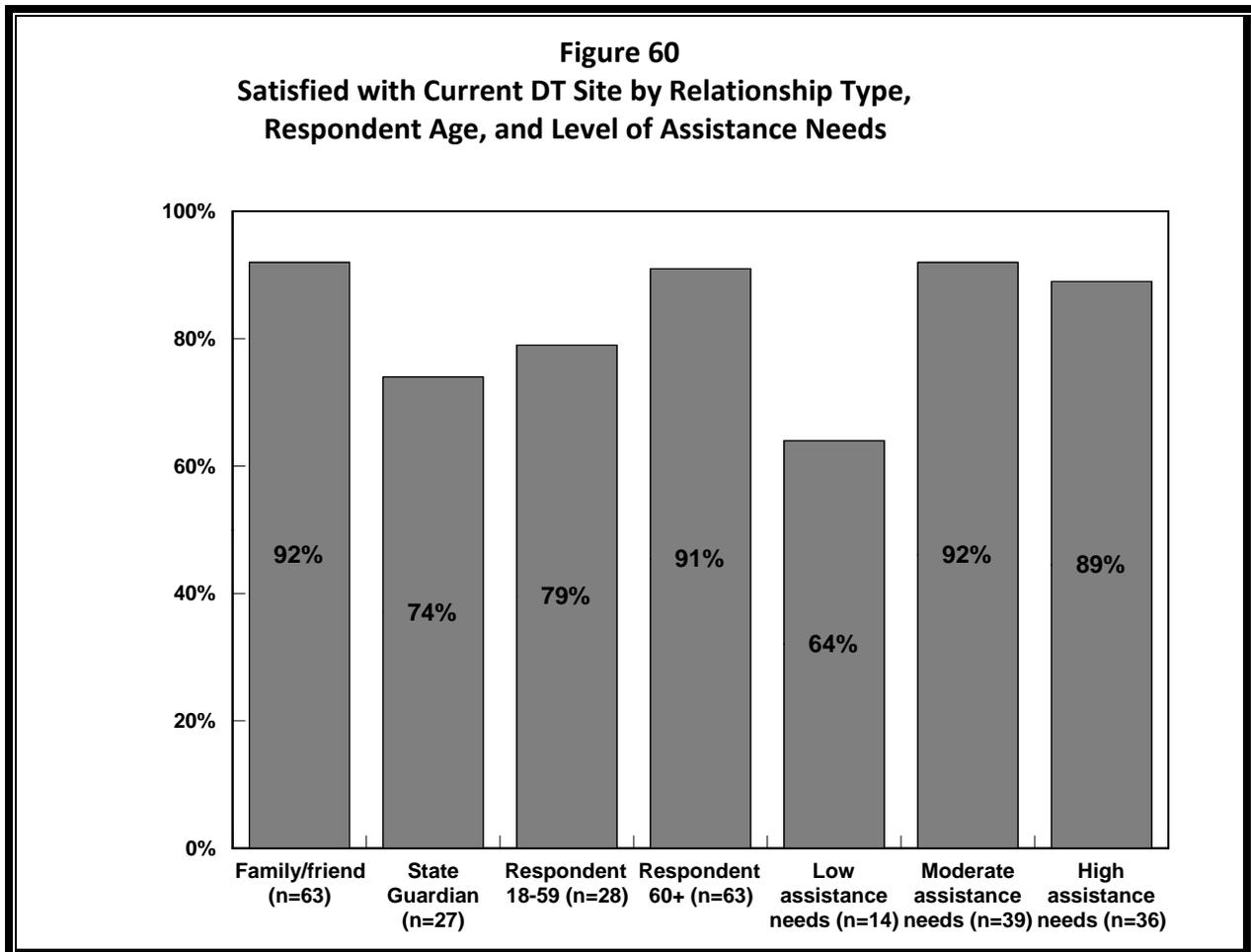
Those reporting a move to a CILA more often reported that their relative/ward got along with housemates (95%), compared to 85% for SODCs and 80% for ICFs/DD. These numbers are similar enough that they do not approach statistical significance for this sample. See Figure 59.



Developmental Training Sites

Respondents were asked whether or not their relative/ward was able to remain at the same Developmental Training (DT) site they had used while at Howe. About a third (33%) replied “yes.” Eleven respondents did not answer this question. The relatives of family/friends more often remained at the same DT site after the transition (44% vs. 7% of state guardian wards).

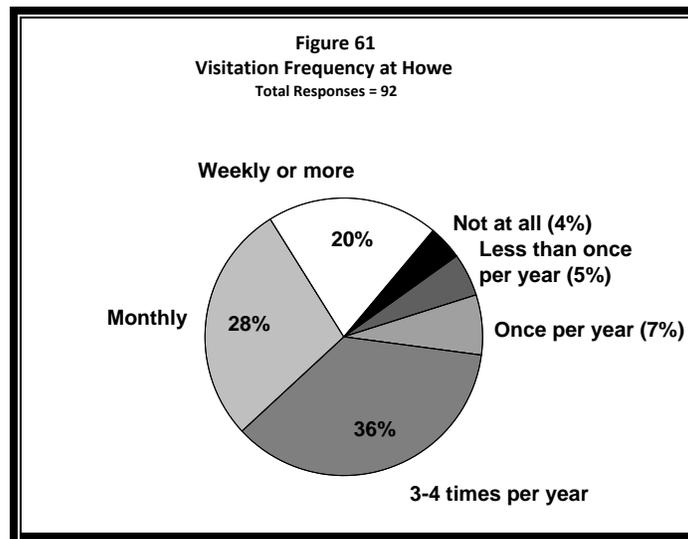
When asked whether or not they were satisfied with the current DT site, 87% of respondents replied they were. However, family/friends were more likely to express satisfaction (92%) than state guardians were (64%). See Figure 91. Respondents aged 60 and over more often reported being satisfied with the current DT site than younger respondents (91% vs. 79%). See Figure 60. Participants with relatives/wards with low assistance needs more often reported being dissatisfied with the current DT site (36% compared to 8% of respondents with relatives with moderate needs and 11% of respondents whose relatives had high assistance needs). See Figure 60.



VISITATION

Visits to Howe

Respondents were asked to describe the frequency of their visits to Howe. Almost 36% reported visiting 3-4 times per year; 28% reported visiting monthly, and nearly 20% reported weekly visits. In addition, 7% reported visiting once per year; 5% reported visiting less than once per year; and 4% reported never visiting. The average score was 3.37 (SD=1.273) indicating that the average respondent visited 3-4 times per year. See Figure 61.



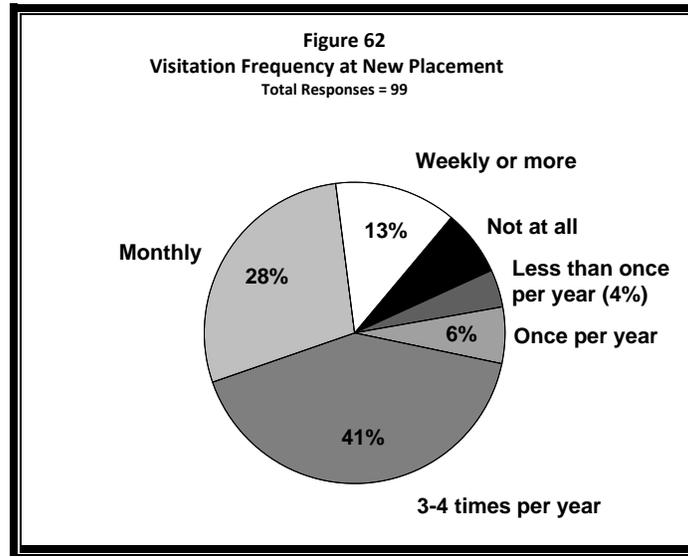
The vast majority (15 of the 18 or 83%) of state guardians visited the individual 3-4 times per year at Howe. One state guardian indicated visiting the person at Howe less than once a year. Two of the 18 guardians (11%) indicated they visited the individual at Howe monthly. Over half (56%) of family/friends (or 41 of the 73 responding) reported visiting Howe at least monthly if not weekly.

Respondents who reported having a relative/ward with low assistance needs (n=15) more often reported having visited Howe at least weekly (47% compared to 11% of respondents whose relative had moderate needs (n=35) and 15% of respondents whose relative had high assistance needs (n=39). These differences were significant at the .01 level ($p = .01$).

Seventy percent of those who reported their family member or ward moved to a CILA (n=20) reported visiting Howe at least monthly compared to 50% of respondents whose family member moved to an ICF/DD (n=6) and 40% of those whose family member moved to an SODC (n=62). These differences were not statistically significant for this sample.

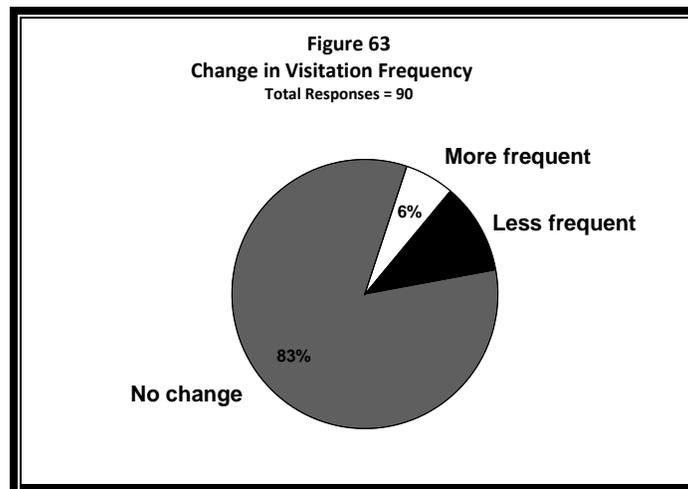
Visitation to New Placement

Respondents were also asked to describe the frequency of their visits to the new placement. Again, a large percentage (41%) reported visiting 3-4 times per year; 28% reported visiting monthly; and 13% reported visiting at least weekly. In addition, 6% reported yearly visits; 4% reported visiting less than once per year; and 7% reported never visiting. See Figure 62.

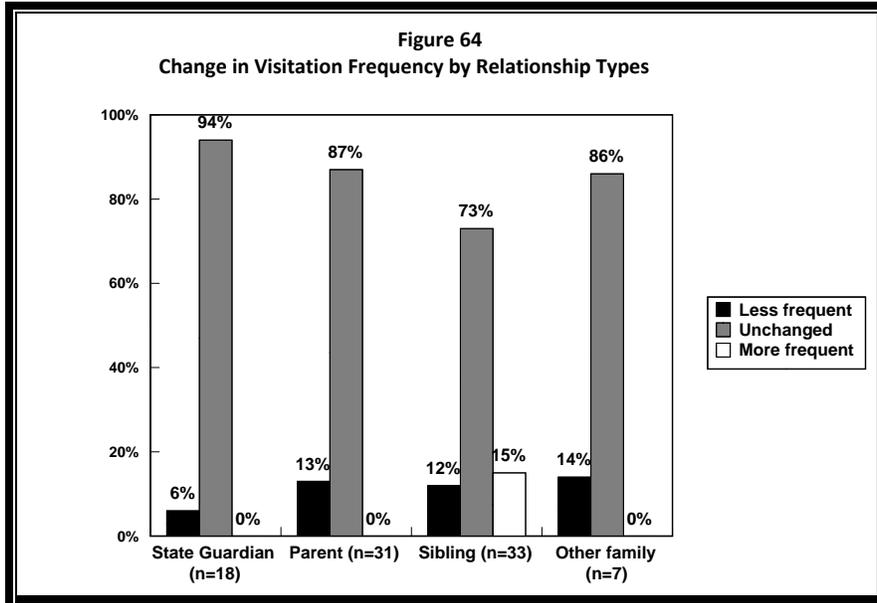


Change in Visitation Frequency

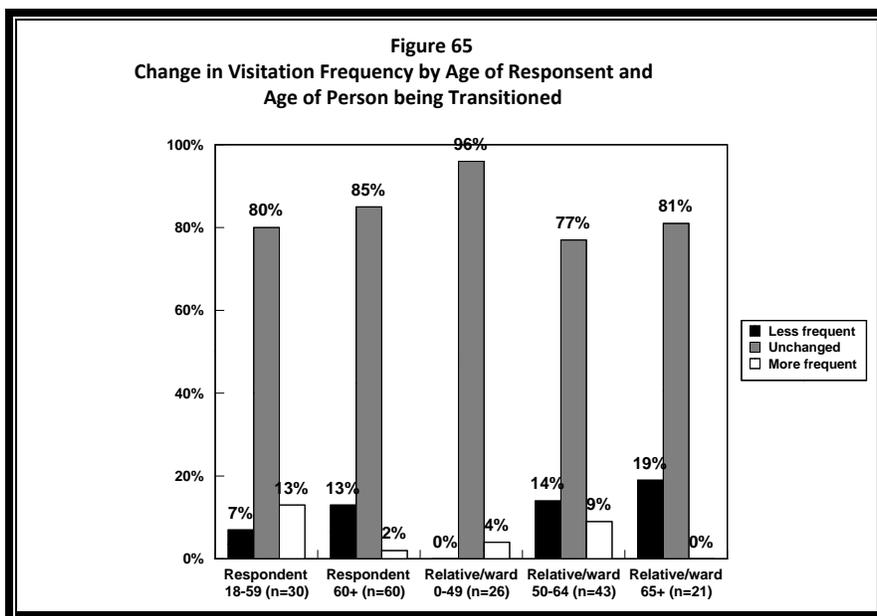
A large majority (83%) of respondents reported no change in their visitation frequency. Approximately 11% reported less frequent visits, and 6% reported more frequent visits. The decrease in visitation frequency was significant at the .1 level ($p = .074$). See Figure 63.



The majority of both friend/family and state guardians reported no change in their visitation frequency. However, among family/friends, only siblings (15%) reported visiting the new placement more frequently than they had visited Howe. See Figure 64.

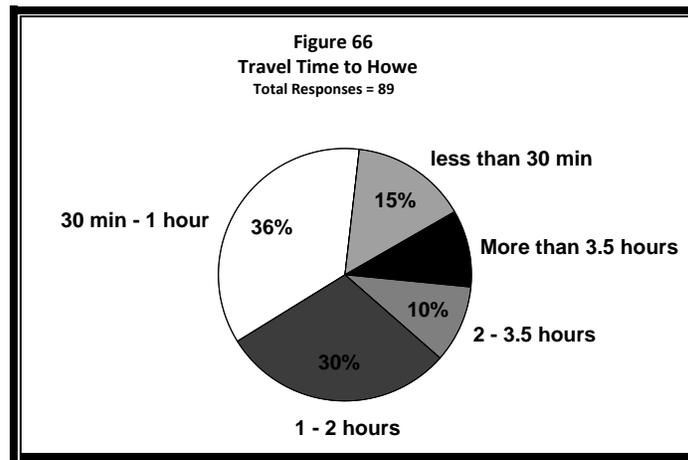


Among all respondents, 13% of respondents under the age of 60 reported that their visitation frequency had increased since the move (versus 2% of older respondents). Older respondents more often reported that their visitation frequency had decreased since the move (13% vs. 7%). See Figure 96. Nineteen percent of those with relatives/wards age 65 and over reported a decrease in visitation frequency. See Figure 65.

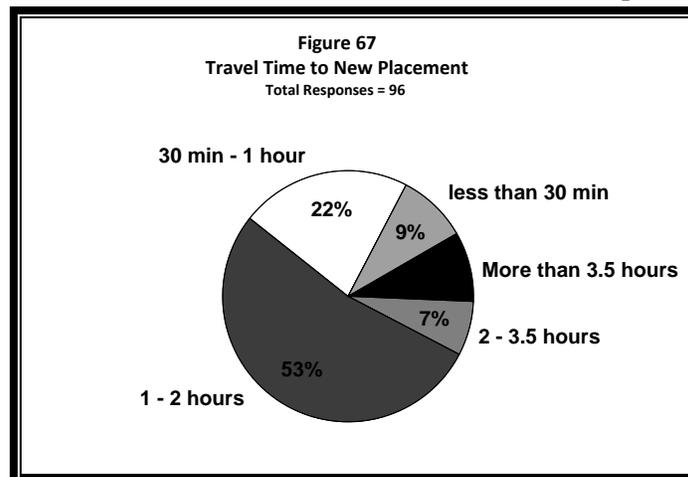


Travel Time to Howe

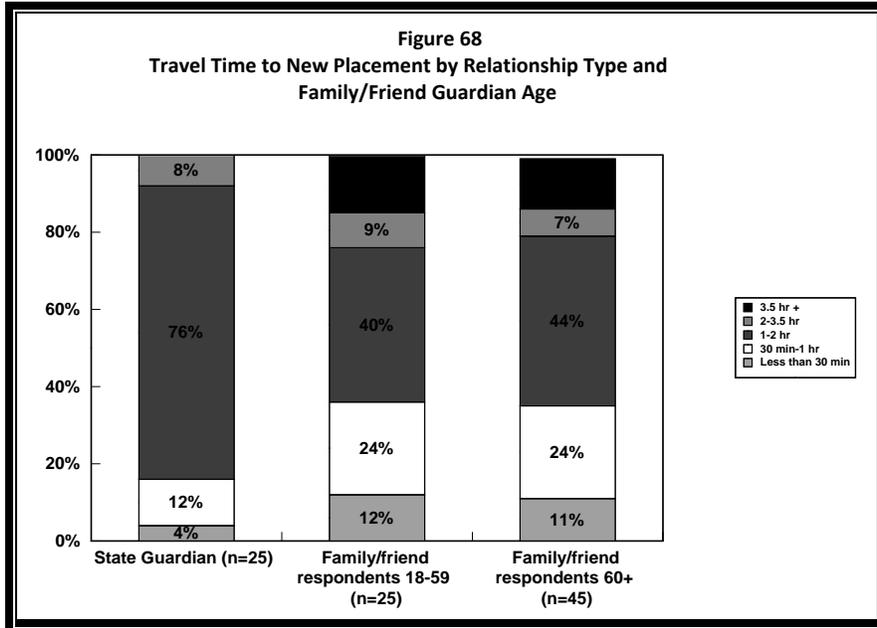
Respondents were asked about the travel time for visitation to Howe. Over half (51%) reported travel times of less than one hour to Howe. Another 30% reported travel times between 1 and 2 hours; 10% reported travel times of 2 to 3 ½ hours; and 10% reported travel times over 3 ½ hours. The average score on this item was 3.18 (SD=2.092), indicating that the average participant traveled between 1.5 and 2 hours for visitation at Howe. See Figure 66. While no state guardians reported a travel time to Howe of more than three and a half hours, 16% of family/friends did.



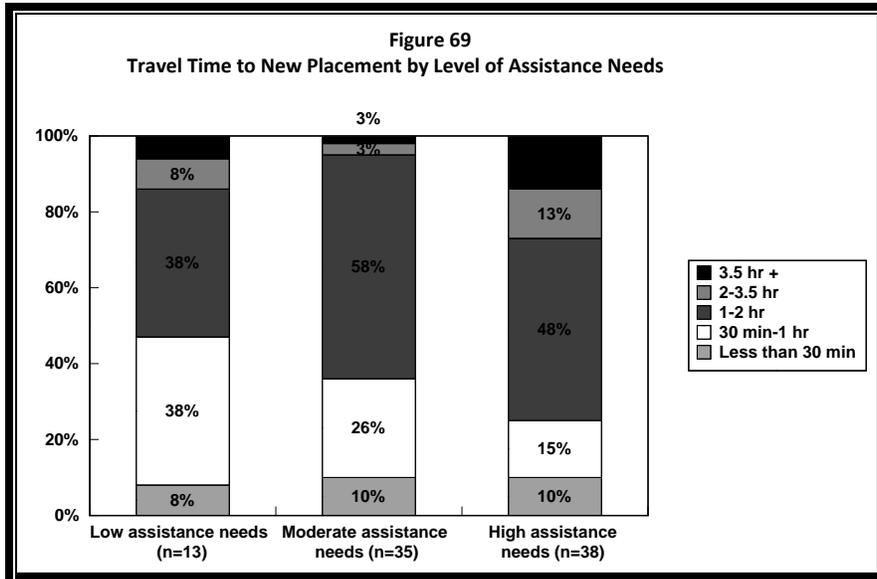
Travel Time to New Placement Respondents were also asked about their travel time to the new placement. A total of 31% reported a travel time of less than one hour. Another 53% reported travel times between 1 and 2 hours; 7% reported travel times between 2 and 3 ½ hours; and 9% reported travel times exceeding 3 ½ hours. The average for this was 3.36 (SD=1.853) still indicating an average travel time of between 1 and 2 hours to the new placement. See Figure 67.



No state guardians reported a travel time to the new placement of more than three and a half hours, while 16% of family/friends under age 60 and 13% of older family members did (Figure 68).

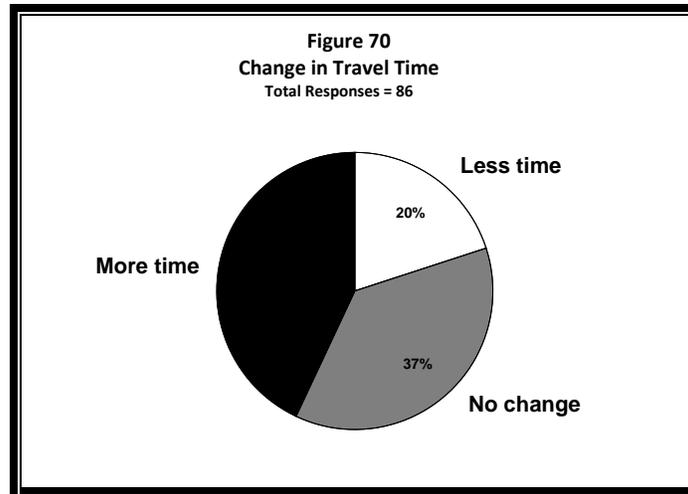


Almost half of the respondents (46%) with relatives/wards with “low assistance needs” reported living within an hour of the new placement, compared to 36% of those with relatives with "moderate assistance needs" and 25% of those reporting relatives with "high assistance needs." See Figure 69.

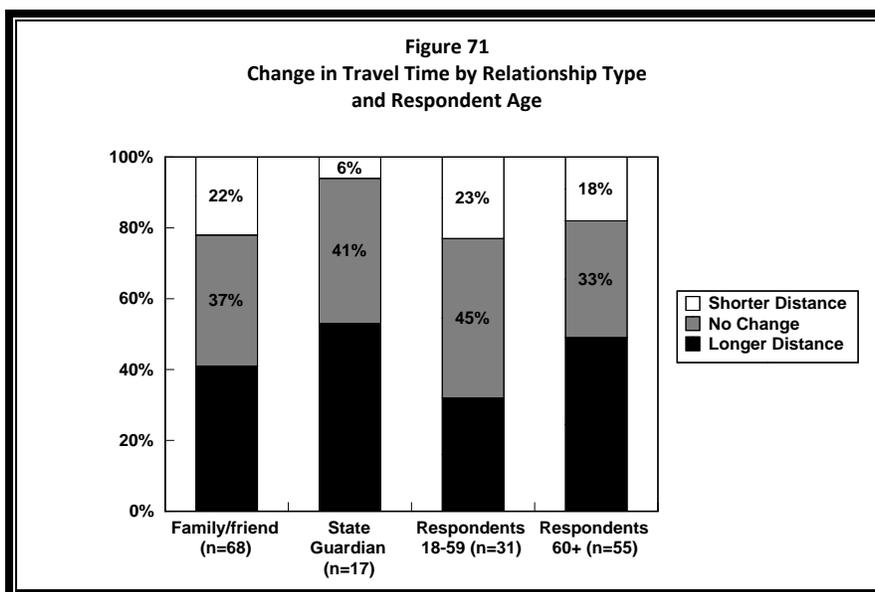


Change in Travel Time

The previous two items allowed us to examine how travel time patterns changed since transition. Around one-fifth (20%) decreased their travel time, 37% reported no change in travel time, and 43% reported longer travel times. The average score on this item was .20 (SD=1.362) indicating a slight increase in travel time for the average family member or guardian. The change in travel time for this sample overall was not statistically significant. See Figure 70.



In regards to changes in travel time, 22% of family/friends reported decreases in travel time, compared to 6% of state guardians. See Figure 71. Nearly 53% of state guardians and 41% of family/friends reported a longer travel time. Almost half (49%) of older respondents reported that their travel time increased with the move, compared to around a third (32%) of younger respondents. These differences were not statistically significant for this sample. See Figure 71.



PHASE II

Phase II of the evaluation involved face to face interviews with individuals who moved out of Howe as a result of its closure for the purpose of gathering qualitative data. DHS distributed a letter explaining the study to former residents (of which a copy was sent to court appointed guardians when applicable). Individuals who were willing to participate in interviews returned a signed consent form giving members of the research team permission to contact them to schedule an appointment for the interview. Interviews were conducted using an interview guide (which can be found in Appendix B) with questions along five core domains:

1. The decision to close Howe;
2. Transition plan;
3. The move;
4. Relationships and
5. Quality of life.

The research team received consent to interview 16 individuals. One individual declined to participate on site, resulting in the interview of 15 individuals in total; eleven males and four females. Members of the research team met the former Howe residents in the setting of their choice, which was typically their developmental training program or their current residence. Of the 15 individual participants, ten were living in an SODC at the time of interview and six were living in a community placement. The 10 people lived at Shapiro (n=5), Murray (n=2), Jacksonville (n=1), Ludeman (n=1) and Fox (n=1). 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. 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. A second research team member, who had conducted all interviews, also reviewed the recordings while simultaneously reading the transcripts. Responses were coded along the five core domains: 1) The decision to close Howe; 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).

The Decision to Close Howe

Most interviewees who responded indicated that they were told about Howe's pending closure by a staff member; one indicated she was informed by her Godmother. One man stated, "...some people told me Howe was closing... Yeah, it was my staff." One man, living in a community-based setting, indicated that he did not recall learning about Howe's pending closure.

Reactions were mixed among respondents. Some respondents indicated they were sad about the closure. A male living in an SODC stated, "I didn't like it...it made me feel very sad... I thought I wouldn't have any more friends." Similarly, another man simply stated "sad" when asked how he felt about it, while another said he felt "mad." One participant indicated that Howe's closure was not a surprise, saying "I knew it was gonna (sic) close. Everybody did." One individual felt it was time for him to move on and said, "It was time to go. I'd been out there a long time." One woman when asked said that she felt "happy."

Participants were also asked about how they picked their new home. One man responded that he chose to move to an SODC after visiting and chose not to tour any other options. A couple respondents indicated they received help from a sibling in picking their new residence. One of these participants also stated she visited at least two homes before making her final decision. Another individual, a man who had relocated to an SODC, indicated that he did not move into his first choice of placements, which was another SODC. He stated that he had "...a whole bunch of friends over there." Faint memory of the process appeared to be a trend among interviewees, as many of them moved over one to two years prior to the interview and details about the closure announcement, choice process and the move were did not appear to be easily recalled. One man currently living at an SODC indicated that he had no memory of visiting his new placement.

Transition Plan

Overall, respondents did not seem familiar with the term "transition plan" and instead seemed to be more familiar with terms such as "annual" or "hab plan" used to refer to the treatment plan developed as a result of their annual team meeting. One interviewee indicated that he helped create his plan, stating, "Yeah. I help with that," while another man shared that he was working on tying his shoes and brushing his teeth as goals. One woman living in a community-based setting said that her goal was to save up for her own phone.

The Move

With respect to the move out of Howe and into their current placements, again, the trend among interviewees appeared to be that it had happened one to two years ago and they had little to offer

in terms of details. Many recalled staff assisting them by packing their belongings and driving them to their new home. Three people named specific staff members that assisting them in their move. For instance, one man stated, “They helped me move. This ... guy who worked at Howe moved everybody here.” One man indicated that his father helped him move to his community placement. One individual complained that his belongings were not satisfactorily delivered to his new home, stating, “No... all my things got left behind... My belt, my pants, and I also have a watch there.” Staff present at the interview, however, was surprised that he hadn’t mentioned his things not arriving with him until the interview. A male resident of a community-based agency recalled that he moved to his new home along with his things in a van. Another man stated he didn’t remember the move while another recalled he didn’t like moving.

Relationships

In some cases, individuals who moved from Howe were able to do so with peers. One man indicated a childhood friend had moved with him, but that friend had died recently. He said, “One died and that made me feel very sad... He was living with me. I took it very hard.” The same individual indicated his “lady friend” moved from Howe to the same SODC as he did and that he was able to see her at work. Others, such as a female and a male both living in community-based settings, said none of their friends moved with them.

Some respondents indicated that they did miss their friends and staff from Howe. One woman said, “I miss my old staff, [I] miss Howe. I miss my old job,” but also said “...I have new friends in [name of city]. Nice new friends.”

Quality of Life

Overwhelmingly, the largest amount of information gleaned from the interviews conducted was with respect to quality of life. This is most likely due to the fact that this question focused on how the individual felt at the time of the interview and did not rely on recollection of events that occurred one to two years ago.

In response to the question, “are you happy living here?” most people answered in the affirmative indicating that they were satisfied with their new placement. One individual said “It’s been good out here, I like it,” of the SODC he had moved to. A couple of individuals, however, expressed dissatisfaction, responding, “Not really” to the same question. Two men in particular expressed that they were unhappy with their current living situation – both stated that they were not happy and didn’t like it there. One man said that he wanted to live in the community, but he was not sure where. He said that he had told his guardian his wishes. Another man also indicated that he wanted to live in a house in the community.

The majority of the other respondents expressed that they did like their new home, stating things such as “I like it ... I have my own TV and stereo and desk and bed and dresser,” and “I like to watch my own TV upstairs in my room.” Some indicated that that they lived two to three hours from their families and saw them on holidays, while another man stated that he goes home

every two weeks. When asked about their satisfaction with the level of privacy offered in their new home, an interviewee stated, “Yep. I’m happy with it... Right now I’m by myself. That’s how I like it... better that way.” Another individual said “I got my own room to myself” and seemed to be pleased with that. One woman living in a community based setting expressed that the “food here is good.”

The majority of those interviewed indicated that they had positive feelings toward the staff who worked with them. One woman said, “Staff is so nice. I like them all... They treat me nice... they help me cook, make my money, they help me do my hair...nice staff.” The two individuals who did not have positive feelings about the staff did not provide specific details other than a general dislike.

Most respondents indicated that they felt safe in their new home and knew who to tell if they were in a situation in which they did not feel safe. One man stated that he did not feel safe, although it was related to his seizure disorder and propensity to fall during seizure activity. He did mention a male peer who physically assaults him, or attempts to, and that he does not like that. This was said in the presence of a staff member who indicated that the situation had been addressed.

Interview participants were asked about what they did during the day. A couple were engaged in competitive community employment – one man living at an SODC works at a restaurant two days a week, while another worked in production at a local workshop. Others participated in center-based vocational and prevocational activities during the day. A few individuals gave specific answers to the question of what they did during the day, “Color, do worksheets for time and math with a calculator. We do money sheets. We do money.” Another stated, “Clean up at the office” while another said “I pick up garbage can stuff.” One man said he did “production...bagging nuts and bolts,” while another said he “like[s] to sit in the rocking chair and dance to music.” When asked if he liked the activities he did during the day, one man said, “We just sit there and do nothing... we just sit there and play with the blocks... I don’t like to do that.” Another man said, “I like to sort. I sort colors.” One woman said, “I’d like to get two jobs - working at a hotel and cleaning up the office. I want to work Fridays, Thursday, Monday, and Wednesday at the hotel.”

The most robust responses resulted from questions about community activities. Participants were able to reflect on their current situation and not have to rely on memories of events that took place one to two years previously. Responses to the question, “Do you participate in activities of your choice in the community?” were plentiful:

“I like to shop and go out for dinner.”

“I like to go to the dollar store.”

“I like to go to the movies.”

“Bowling Sunday Best Buddies”

“I got a new bike... It’s brand new, I just bought it. It’s silver...[I ride it] around here, around campus... in the summer.”

“I got a new soccer ball this summer. I play outside in the yard.”

“Go out to eat and to the movies. We went out to the movies a couple weeks ago.”

“Eat out.”

“I like to do a lot of stuff. I like to listen to music. Mixes, dance music.”

“I like to go to RadioShack.”

“I like to go bowling.”

Statements also included activities in which the individual would like to participate, such as: “I want to go shopping downtown, Taste of Chicago.”

One man, currently living in an SODC, indicated that he did not get to choose the community activities in which he participated. He relayed that the person providing transportation for the activity makes the choice. He also said that he likes to go bowling but doesn’t go as often as he would like. Another woman, living in a community setting, stated that she does not go out and do anything for fun although she goes to the grocery store on the weekends.

Additionally, when asked if they were happy, respondents indicated both satisfaction and dissatisfaction with their current living situation. Overall, many respondents living in an SODC expressed desire to live in the community. In response to the question, "do you ever think about living in an apartment in the community?", one man living in an SODC answered, “I don’t want to live here forever, I want to go... Yeah. I want to live with guys like me.” He further asked, “...when I get out of here could I get a yard? I want to work on a yard... I like to water plants and pull weeds and garden vegetables. I like to pull weeds. I like to garden.” Another male SODC resident stated, “I want to move [into a group] home. That’s all I’m working on... I’m on the waiting lists for the homes if somebody moves out.” A third male SODC resident indicated he’d like to move into the community, while a fourth stated that he didn’t think about living in the community. Two women living in a community-based setting, indicated that they liked their new home. One said, “I don’t want to move, I wanna stay where I[‘m at].” She expanded on that thought stating, “I’m not ready to live on my own yet. It’s too hard for me... too much to do on my own.”

One common theme among a few of the men who had moved to another SODC was dissatisfaction with the availability of employment. While at Howe, these gentlemen had worked in the laundry department and indicated that they had made "good money." In the SODC they were living in at the time of the interview, however, such income generating work was not readily available. This was distressing to these men who had become accustomed to having spending money. The man that works at the restaurant at another SODC said that his money was kept locked in a safe and that he did not have access to it except through a staff member. One

woman living in a community-based setting stated that she did not have any money or a bank account.

In general, individuals who had transferred to a community-based setting indicated satisfaction with their new home and did not express a desire to move. Individuals living in another SODC, however, expressed an overall desire to move into the community and obtain gainful employment. Few individuals were able to share details of their experiences such as when they found out that Howe was closing other than those emotional in nature. Most respondents indicated that they felt sad about moving and that was due to fear of losing friendships of peers and staff members alike.

One limitation of Phase II was with respect to the length of time that had passed since the move and the time of the interview. Future evaluations may seek to conduct interviews of individuals affected by the closure closer to the time of the announcement and actual move.

SUMMARY

The Howe Developmental Center closed on June 21, 2010. One hundred and eighty-one individuals moved to seven other State Operated Developmental Centers (SODCs) in Illinois; 45 moved to Community Integrated Living Arrangements (CILAs); and 19 moved to Intermediate Care Facilities for persons with Developmental Disabilities (ICFs/DD). One individual moved to a family CILA and one individual moved out of the state.

In the spirit of continued monitoring of outcomes for individuals transitioning out of Illinois SODCs, the Department of Human Services' Division of Developmental Disabilities contracted the Institute on Disability and Human Development (IDHD) at the University of Illinois at Chicago (UIC) to conduct an evaluation of stakeholders' experiences of the Howe closure.

The primary objective of the present evaluation was to examine stakeholders' experiences with the closure and transition process and outcomes as well as the individual's satisfaction with their current living situation. Information was collected in two phases from both individuals who moved out of Howe as well as guardians/family members who had a relative/ward living at Howe when closure was announced. Two hundred and forty-four surveys were mailed to family members and guardians. One hundred and three were returned to UIC, a response rate of 42%. A third (33%) of respondents identified themselves as the sibling of the person transitioned out of Howe, 31% reported being a parent, 6% other family, 3% reported being a friend, and the remaining 27% identified themselves as public guardians. In addition, interviews were conducted with 15 former Howe residents, including 10 who went to SODCs and 5 to CILAs.

KEY FINDINGS

What are some of the basic trends associated with closure, transition, and placement?

- Fifty-eight percent (58%) of respondents reported their family member/ward had lived at Howe for 20 or more years.
- 71% of respondents reported their loved one moved to an SODC, 22% to a CILA, and 6% to an ICF/DD – these percentages are representative of the total population that moved from Howe.
- Fifty six percent (56%) of respondents felt their family member was better off now than at Howe, 34% felt their relative/ward was the same, and 11% felt their family member/ward was worse.
- Only one of 92 respondents indicated their family member had no housemates at the new placement.
- Visitation really only changed for people who used to visit weekly at Howe (went from 20% of sample at Howe to 13% of sample at new setting). Now this portion of respondents appears to be visiting quarterly.

How satisfied are family/guardians with the closure and its outcomes?

- Most respondents (80%) were dissatisfied with the initial decision to close Howe. Among family/friends, 89% reported dissatisfaction.
- After the closure the overall percent of family/guardians dissatisfied with the closure dropped to 63%.
- Over half of all respondents (62%) indicated that they did not change their feelings about the decision to close Howe. Over one-third (36%) now feel more positively about the decision and a small percentage (2%) now feel more negatively about it.

What were the differences in attitudes towards closure and to community placements between family and state guardians?

- State guardians more often reported being dissatisfied with the transition process than family/friends (67% vs. 28%).
- While 58% of state guardians responded that they felt community placement could be beneficial to their ward, none of the wards of state guardians who responded to the survey reported a move to a CILA.
- Prior to the closure of Howe, only 14% of family members felt the community would be a beneficial place for their loved one. The percentage dropped to 8% if you narrowed it down to family respondents over age 60.
- Most of the state guardians (86%) reported visiting zero agencies prior to making a placement decision compared to only 26% of family/friends. However, 79% of state guardians indicated that they had visited the new placement prior to the transition,

suggesting that state guardians may have visited these agencies prior to the announced closure of Howe.

To what extent did age and level of need affect the type of setting people moved to and family/guardian attitudes to the closure, family placements, and closure's outcomes?

- Among all respondents, higher levels of assistance needs were associated with increased levels of dissatisfaction with the initial decision to close Howe (74% of respondents whose family member had high assistance needs reported being "very dissatisfied" versus 55% of moderate assistance needs and 40% with low assistance needs).
- 20% of those with high assistance needs moved to a CILA.
- Among all respondents, those with older relatives/wards (age 60+) more often reported some level of dissatisfaction with the closure process (56%).
- Twenty-six percent of family members did not visit the new placement -- this percentage increases to 33% if you limit responses to family members over the age of 60. Approximately 16% of respondents under the age of 60 did not visit the new placement.
- Respondents with relatives aged 65 and over all felt that their relative was better off (or the same) at their new placement than they were at Howe; of those with relatives between the ages of 50 and 64, 13% felt their relative was doing worse; and of those with relatives younger than 50, 16% felt their relative was doing worse.

To what extent did type of setting influence family/guardian attitudes to closure, community placements and closure outcomes?

- Over three-quarters (77%) of those reporting a move to a CILA reported having a positive opinion about the benefits of community placement after closure.
- For those respondents whose family members moved to a CILA, 53% reported a positive change in their opinion about the benefits of community placement for their family member (47% did not change their opinions on community supports over time).
- Over 95% of respondents whose family member moved to a CILA reported visiting the new home prior to the move.

What are the lessons learned regarding family/guardian supports for the transition?

- The transition hotline is underutilized; 50% did not use the service and 27% did not know about the service. 17% found the service helpful, while 6% did not. Lack of awareness of the hotline was especially true for family members (30% were unaware of hotline) and non-white respondents (50%). \

What do residents feel about the closure, transition and current placement?

- Residents had mixed reactions regarding the closure.
- Several residents expressed missing friends and staff they had at Howe.
- Many respondents living in the SODCs expressed a desire to live in the community

- Residents who were in the community expressed a desire to remain in their current residence.
- A key theme was the desire of residents to obtain employment.

APPENDIX A

**An Evaluation of the Closure of Howe Developmental Center
Family Satisfaction Survey
The University of Illinois**

1.	What relation do you have with the individual who moved out of Howe?					
	<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"/>	Bachelors degree
	<input type="checkbox"/>	Masters degree	<input type="checkbox"/>	Doctorate	<input type="checkbox"/>	Other _____

7.	How old is your relative that transitioned from Howe?	_____
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8.	Does your relative need assistance for 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

9.	How many years did your relative live at Howe?	_____
----	--	-------

10.	How satisfied were you with the services your relative received at Howe?			
	<input type="checkbox"/>	Very satisfied	<input type="checkbox"/>	Somewhat satisfied
	<input type="checkbox"/>	Somewhat dissatisfied	<input type="checkbox"/>	Very dissatisfied

11.	How satisfied were you initially with the decision to close Howe?			
	<input type="checkbox"/>	Very satisfied	<input type="checkbox"/>	Somewhat satisfied
	<input type="checkbox"/>	Somewhat dissatisfied	<input type="checkbox"/>	Very dissatisfied

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

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

14.	I had influence over how my relative's transition out of Howe was carried out?			
	<input type="checkbox"/>	Strongly agree	<input type="checkbox"/>	Somewhat agree
	<input type="checkbox"/>	Somewhat disagree	<input type="checkbox"/>	Strongly disagree

15.	I feel my 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

16.	The closure process:					
	<input type="checkbox"/>	Moved too quickly	<input type="checkbox"/>	Moved quickly	<input type="checkbox"/>	Moved at a good pace
	<input type="checkbox"/>	Moved slowly	<input type="checkbox"/>	Moved too slowly		

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

18.	Currently, how much do you agree with the following statement: My relative would benefit from a move out of an institution and into a community placement					
	<input type="checkbox"/>	Strongly agree	<input type="checkbox"/>	Somewhat agree	<input type="checkbox"/>	Somewhat disagree
	<input type="checkbox"/>	Strongly disagree	<input type="checkbox"/>	Not applicable, as my relative is currently in a community placement		

19.	Prior to the Howe closure, had you ever received information on other residential options?	<input type="checkbox"/>	Yes	<input type="checkbox"/>	No
-----	--	--------------------------	-----	--------------------------	----

20.	Did you receive adequate information on service providers upon which to make a choice?	<input type="checkbox"/>	Yes	<input type="checkbox"/>	No
-----	--	--------------------------	-----	--------------------------	----

21.	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
-----	--	--------------------------	-----	--------------------------	----

22.	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

23.	Was your relative placed at your first choice of settings?	<input type="checkbox"/>	Yes	<input type="checkbox"/>	No
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24.	How helpful was the Transition Hotline?					
<input type="checkbox"/>	Very helpful	<input type="checkbox"/>	Helpful	<input type="checkbox"/>	Not helpful	
<input type="checkbox"/>	I did not use the Transition Hotline		<input type="checkbox"/>	I did not know there was a Transition Hotline		

25.	How helpful was the Family Liaison?					
<input type="checkbox"/>	Very helpful	<input type="checkbox"/>	Helpful	<input type="checkbox"/>	Not helpful	
<input type="checkbox"/>	I did not use the Family Liaison		<input type="checkbox"/>	I did not know there was a Family Liaison		

26.	Did you receive timely updates on your relative's transition from Howe?	<input type="checkbox"/>	Yes	<input type="checkbox"/>	No
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27.	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	

28.	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 _____		

29.	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

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

31.	As compared to when your relative lived at Howe, do you think s/he is better or worse off now?		
	<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	

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

33.	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	

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

35.	Staff at the new placement:				
<input type="checkbox"/>	My relative likes the staff that work with him/her	<input type="checkbox"/>	My relative does not like the staff that work with him/her	<input type="checkbox"/>	I don't know/ am not sure

36.	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"/>	I do not have housemates		

37.	Was your relative able to remain at the same Developmental Training (DT) site that they went to while living at Howe?	<input type="checkbox"/>	Yes	<input type="checkbox"/>	No
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38.	Are you satisfied with your relative's current Developmental Training (DT) site?	<input type="checkbox"/>	Yes	<input type="checkbox"/>	No
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39.	While your relative lived at Howe, how frequently did you visit him/her?										
<input type="checkbox"/>	Weekly or more	<input type="checkbox"/>	Monthly	<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

40.	How long did it typically take you to travel from your home to Howe?						
<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

41.	How frequently do you visit him/her now?										
<input type="checkbox"/>	Weekly or more	<input type="checkbox"/>	Monthly	<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

PLEASE TURN OVER PAGE TO CONTINUE

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 Howe has had on your family, including any examples that would support your description.

Thank you for taking the time to answer the questions.

APPENDIX B

Evaluation of Howe Developmental Center Closure

Interview Guidelines for Individuals who transitioned out of Howe Developmental Center

Areas of Inquiry

1. The Decision to Close Howe

- a. How did you first learn that Howe was closing?
- b. How did you feel when you heard Howe was closing?
- c. Did you feel as though you had a choice of where you would move?
(if they feel they had a choice):
 - 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?
 - What types of help did you receive while making the choice of where to move?
 - Did you visit (name of place individual is currently residing) before you moved here?
 - Did you talk with any other providers? Was it helpful to talk to them?
- d. Did you move to where you wanted to go?

2. Transition Plan

- a. Do you have a transition 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?
 - Did you feel like you knew what was happening during the time Howe was closing? Did you feel like people communicated with you? (were you kept in the loop)?
- b. Who helped you pack your things?
- c. Did your things travel with you when you moved, or did they come separately?
- d. How did you get here (car, ambulance, etc)?

- e. Did you get all your things delivered to your new house?
- f. Is there anything that you can think of that might have made the move easier?
- g. 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 Howe move here also?
- b. Do you keep in touch with friends that moved to other places from Howe?
- c. Did you have any problems with your supports or services during your move to your new home?
- d. Have you met new friends at your new home?
- e. 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 miss Howe?
 - Do you like the location of your present home?
 1. Do you like the community? Is it close to your family? Friends?
 - Do you feel like you have privacy in your new home?
- 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 personal property is safe?
- c. Respect
 - Are staff respectful of you?
 - Do staff explain things to you in ways you understand?
- d. How long do you think you'll stay here?
- e. 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)?
 - Do you participate in activities of your choice in the community (go to the movies, park, events, etc.)
 1. If not, what barriers are there that prevent you from participating?
 2. Do you have spending money?
- f. 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?
 - g. 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?
 - 1. What is different?
 - What do you like here?
 - What do you wish was different?
 - Do you miss Howe?
 - Do you like the location of your present home?
 - 1. Do you like the community? Is it close to your family? Friends?
 - Do you feel like you have privacy in your new home?
 - 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 personal property is safe?
 - c. Respect
 - Are staff respectful of you?
 - Do staff explain things to you in ways you understand?
 - d. How long do you think you'll stay here?
 - e. 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, what barriers are there that prevent you from participating?
 - 2. Do you have spending money?
 - f. Do you feel happy with your life? If not, is there something that you would change?

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