

**Seven Years Later: A Satisfaction Survey of the Families of the Former
Residents of Hissom Memorial Center**

Brief Report Number 9
Of a Series on the Well Being of People with
Developmental Disabilities in Oklahoma

Submitted to:

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“In 1990, these people were surrounded by walls.
In 1999, they're surrounded by doors.”

The quotation above is from David Loconto, a graduate student at Oklahoma State University. When he wrote this in 1995, Mr. Loconto was studying the well-being of people who moved from Hissom to community. He personally visited more than 200 Hissom class members in 1995.

Executive Summary

This is the report of the results of a survey performed in 1998 and 1999 with the closest relatives of the former residents of the Hissom Memorial Center. Hissom closed in 1994, under the terms of a Federal court order issued by Judge James Ellison in 1987.

Over the past 9 years, Oklahoma has supported rigorous scientific study of the well being of the people who once lived at Hissom. With two cooperative contracts, one with Oklahoma State University, and one with the Center for Outcome Analysis, the Developmental Disabilities Services Division has documented major improvements in qualities of life among the people after they moved to community homes. This report contains selected results of a mailed survey of the families of the people who once lived at Hissom Memorial. In this report, we focus on the general question, "Are the people better off?" in the opinion of the families.

Past research at the national level has clearly established the fact that families of people in public institutions are highly satisfied with these facilities before their family member is moved into the community (Spreat, Telles, Conroy, Feinstein, & Colombatto, 1987). Most families are opposed to changes, and most are particularly opposed to community placement before community placement occurs. The nation's first report of changes in family attitudes after movement from the institution to the community was published by Latib, Conroy and Hess (1984). They surveyed Pennsylvania's Pennhurst families before and after community placement. They found that the families' initial opposition changed dramatically to overwhelming satisfaction with, and support for, community living after their relative had been established in a community home. Subsequent research in this area has supported these findings.

In the summer and fall of 1998, the Center for Outcome Analysis mailed a survey to the closest relative, friend, or guardian of each person who was considered to be a Hissom class member (total number of surveys mailed, 814). The total number of completed surveys from both mailings that were returned was 303. This represented a final overall response rate of 46.6%. Over the past 20 years, we have surveyed tens of thousands of families of people with developmental disabilities, and we fairly consistently obtain a response rate just under 50%. The rate of 46.6% was therefore judged to be acceptable.

The Hissom family survey was designed with one consistent question in mind: “Are the class members better off than they were at Hissom?” The survey therefore included questions about beliefs, attitudes, memories of past attitudes, satisfaction, perceptions of qualities of life, perceptions of changes in qualities of life, positive perceptions, negative perceptions, aspirations, and outcomes that were valued by the families for their relative.

The respondents to this survey were most often mothers, followed by mother and father responding together, then siblings. The ages of the responding relatives ranged from 26 to 90, with an average age of 62 years. Their relatives had lived at Hissom an average of 12 years. The average age of the Class Members was 37 years old. More than 50% of these relatives said their relative had moved to a Supported Living situation, 13 % said their relative had moved to a Group Home, and 14% of these respondents said their relative was now living in his or her own home or apartment.

In terms of family contact, contact by telephone was the most frequent method, at about 7 times a month. Visits to the person at his or her community home were also fairly frequent at almost 3 per month. The person was picked up by family members and taken on an outing just over once a month. This group of families attended an average of 4 program planning meetings a year, and gave consent for medical care an average of twice a year.

When family members were asked if they were initially “For” or “Against” the idea of community placement, initial attitudes were almost equally distributed on the positive and negative sides of the issue. When asked a question to test for the change in attitudes, “How do you like your relative’s new home?” we saw an extraordinary pattern. If we take the families who said, “Don’t Know” or who left this item blank from the percentages, we find that the figure for some degree of positive feeling about their relative’s new home is 98.9%.

In our research over the years, we have become accustomed to very positive family feelings about community living. However these results are the most positive we have ever seen. This is in keeping with the fact that, overall, the positive outcomes of deinstitutionalization in Oklahoma have been the most compelling this research team has ever seen (Conroy, 1999). We found that when Judge Ellison handed down his decision to close Hissom, 38.7% of the families were opposed to movement to the community. Now the families are about 90% in favor of community living.

When asked about the perceived quality of life for their relative “Then” (while at Hissom) and “Now” (in the community), we found that on average families feel that their relatives are “better off” in every way on the 15 quality of life dimensions we measured. When we looked at which dimensions of quality of life showed the largest increase from “Then” to “Now”, it was intriguing and instructional to note this increase occurring in the area of Privacy. The second largest gain was in Overall Quality of Life. The third largest change was in Making Choices. The smallest changes were in Health, Relationships with Friends, and Relationships with Family.

When using the “Quality of Life Changes” scale to test findings about perceived quality of life, we saw a difference of a magnitude we have not seen before. The “Now” score was found to be just below double the “Then” score. There can be little doubt of the fact that Oklahoma’s Hissom families are happy with the move from the institution to the community. Even those families that opposed the change are now convinced that it was wise to make the change. Included in this report as well is a random sample of families’ responses to the question, “What is the biggest change your relative has experienced since leaving Hissom?” which helps to illustrate the changes family members have seen in their relative since he or she moved from the institution into the community.

When asked what the five most “valued outcomes” are that the families have for their relative, the most important was Love, followed by Health, Safety, Freedom from abuse, and the fifth, Medical attention (this was closely related to Health). At the bottom of the family values hierarchy were Choice-making, Self-determination, Earning money, Having boyfriends/girlfriends. Integration and Inclusion were near the bottom of the hierarchy, as was Community Acceptance – possibly because these families cannot even imagine their sons and daughters being active in any kind of community life. We interpret from the “Valued Outcome” data that the values of professionals are quite disparate from the values of families. We suspect we will find in future research that both family and professional value systems are markedly different from those of the people themselves.

Future reports will address the information in the Family Survey about Day Programs, family perceptions of Case Managers, the families review of the extent to which they were “kept informed” during the closure process, and analyses of power, control, and self-determination in the eyes of the families.

Introduction

This is the report of the results of a survey performed in 1998 and 1999 with the closest relatives of the former residents of the Hissom Memorial Center. Hissom closed in 1994, under the terms of a Federal court order issued by Judge James Ellison in 1987.¹

The court order allowed the hundreds of people who were residing at Hissom to have a chance at “regular lives.” This meant that the people were given a chance to live in regular homes, in regular neighborhoods, and to take part in productive activities in regular settings, and to be free to experience relaxation and recreation in the locations and modes available to any citizen.

In his order Judge Ellison wrote:

This trial Court, sitting in Oklahoma in 1987, upon consideration of the overwhelming evidence ... must conclude that constitutional federal and statutory requirements now dictate removal of the institution as a choice of living environment for such individuals.

¹ A lawsuit to improve the lives of the people who lived at Hissom began in 1985: *Homeward Bound Versus Hissom Memorial Center*. The case was filed in the United States District Court for the Northern District of Oklahoma. The case went to trial in 1987. After the trial was complete, Judge James Ellison issued his Opinion and Order on July 24, 1987 (Ellison, 1987).

Over the past 9 years, Oklahoma has supported rigorous scientific study of the well being of the people who once lived at Hissom. (Oklahoma has also extended this scientific work statewide, to include nearly all people receiving supports from public sources.) With two cooperative contracts, one with the Oklahoma State University, and one with the Center for Outcome Analysis, the Developmental Disabilities Services Division has documented major improvements in qualities of life among the people after they moved to community homes (Bell, Dodder, & Murray, 1999; Conroy, 1999).

This report contains selected results of a mailed survey of the families of the people who once lived at Hissom Memorial. The survey form was fairly lengthy, and contained more information than can easily be contained in a single Brief Report. In this report, we focus on the general question “Are the people better off?” in the opinion of the families. Other areas covered in the survey, such as case manager interactions, power and control, self-determination, information sharing, and jobs and day programs, will be the topics of future reports in this series.

Prior Research: Families and Deinstitutionalization

Surveys of the families of people with developmental disabilities are becoming a more frequently used and valued tool for assessing the quality of services (Arc-US, 1989; Conroy & Bradley, 1985; Covert, Hess, & Conroy, 1985; Larson & Lakin, 1991). The present efforts to monitor family perceptions of the well being of Hissom class members who moved to community homes should be seen as part of that trend.

Past research at the national level has clearly established the fact that families of people in public institutions are highly satisfied with these facilities (Spreat, Telles, Conroy, Feinstein, & Colombatto, 1987). Most families are opposed to changes, and most are particularly opposed to community placement.

In one of the earliest studies, Klaber (1969) surveyed parents of people in institutions in Connecticut. He found that more than three fourths of them believed that the institutions were extremely high quality. He concluded that “The parents ... were convinced of the excellence of the facilities in which their children were placed ... The praise lavished on the institutions was so extravagant as to suggest severe distortions of reality in this area.”

Brockmeier (1975) reported similarly high levels of satisfaction, coupled with skepticism about community-based care, among families of people in Nebraska institutions. Payne (1976) discovered the same situation in Texas. Payne was also the first to identify a “deinstitutional backlash.” He characterized the backlash group as a

loosely knit countermovement of various local and statewide associations of parents organized in support of institutions as opposed to community residential facilities.

Willer, Intagliata, and Atkinson (1979) reported overwhelming satisfaction among families of institutionalized people in New York state.

Meyer (1980) found that over 70% of families of people in an institution in Western Pennsylvania were satisfied with the services provided by the facility, and they opposed the idea of community placement.

Keating, Conroy, and Walker (1980) found as part of the Pennhurst Longitudinal Study that 83% of families were “satisfied” or “very satisfied” with Pennhurst, even at the height of court and media criticism of Pennhurst. Moreover, 72% strongly opposed the idea of community placement.

Frohboese and Sales (1980) reported that families in Nebraska believed the state institution to be the least restrictive alternative feasible for their relatives. They perceived greater freedom of movement, independence, and safety within the institution. The greatest concern expressed by these families about deinstitutionalization was their perception of the lack of permanence of the community settings. These authors also described the possibility of legal and ethical conflict between the rights of parents and the rights of people with disabilities.

Atthowe and Vitello (1982) detected similar feelings among families in New Jersey. In their survey, 54% expected no more than custodial care, and 91% said the

institutional care was adequate or better. More than 80% wanted their relatives to remain in New Jersey's institutions.

Conroy (1984) surveyed the families of 1611 people living in institutions in Pennsylvania who had been “nominated” for movement to the community. No fewer than 91% of families were “satisfied” or “very satisfied” with institutional services, and 81% were “opposed” or “very opposed” to the idea of community placement.

Conroy (1987) found in Georgia that 72% of the families of people at Georgia Retardation Center were “Very Satisfied” with services provided to their relatives. They overwhelmingly opposed the idea of movement to community services.

Spreat, Telles, Conroy, Feinstein, and Colombatto (1987) conducted a national survey of the families of people in public institutions. The survey revealed very high satisfaction with the institutional settings, plus resistance to community services. Overall, 61% of families rejected the idea of “a group home of about six beds, located in a regular residential area, staffed 24 hours so that clients are never left alone, and from which every client goes to a day program (school, workshop, job).” The survey also showed that resistance to community services was higher among families of people with the most severe impairments.

The nation's first report of changes in attitudes after movement from institution to community was published by Latib, Conroy, and Hess (1984). They surveyed Pennsylvania's Pennhurst families before and after community placement. They found

that the families' initial opposition changed dramatically to overwhelming satisfaction with, and support for, community living.

Covert, Hess, and Conroy (1985) surveyed families after their relatives left the Laconia State School in New Hampshire. According to family recollections, only 38% had been “satisfied” or “very satisfied” with the situation at Laconia, whereas 84% said they were satisfied or very satisfied with their relatives' current community residences.

Conroy and Wang (1987) reported on Connecticut research tracking more than 1300 people. For people who moved from institutional to community settings, family satisfaction and the perceived happiness of the relative increased sharply.

Conroy, Lemanowicz, and Bernotsky (1991) extended the prior work of Conroy & Wang (1987). They surveyed the families of 101 deinstitutionalized people in Connecticut before and after community placement. The survey contained nine items related to quality of life and satisfaction (e.g., satisfaction with the home, with day program, food, privacy). All nine items increased significantly, with improved privacy and satisfaction with the residential setting showing the largest positive changes.

Grimes and Vitello (1990) examined the attitudes of 32 families of deinstitutionalized people who had been living in the community for 3 to 7 years. Preplacement data on these families (Atthowe & Vitello, 1982) had shown a high level of satisfaction with institutional services and strong opposition to community placement. The postplacement survey revealed a significant change toward more positive family attitudes toward deinstitutionalization.

Temple University's 1990 survey of all the families of people who once lived at Pennhurst (Lemanowicz, Levine, Feinstein, & Conroy, 1991) revealed that only 6 of the 420 responding families were “Strongly Dissatisfied” with community living. Many of the families wrote comments describing how surprised they were with the quality of life enjoyed by their relatives in community homes. Many wrote that they were amazed that they had ever opposed the move from institution to community.

Larson and Lakin (1991) wrote a review article based on all of the family deinstitutionalization attitude studies of the preceding two decades. They performed a meta-analysis upon the results of 27 such studies which examined the attitudes and perspectives of parents of currently or formerly institutionalized people. Larson and Lakin summarized: “The clearest message in these studies is that the overwhelming majority of parents become satisfied with community settings once their son or daughter has moved from the institution, despite general predispositions to the contrary.”

Methods

Procedures

In the summer of 1998, we mailed a survey to the closest relative, friend, or guardian of each person who was considered to be a Hissom class member. The list was provided to our group by the Developmental Disabilities Services Division. The list contained 814 names and addresses. These represented all known primary contact people for the Hissom class members. Many of the class members had no primary contact or relative. This is typical for people who have been institutionalized; many have lost all contact with families, and have no other allies who could speak knowledgeably about their well being.

We mailed survey forms to all 814 contact people. However, 163 envelopes were returned, marked as “No Such Number,” “Addressee Unknown,” “Attempted Not Known,” “Moved, No Forwarding Address,” or “Forwarding Order Expired.” This left a pool of 650 families who may have received the survey. (Non-deliverable letters may not always be returned to the sender, depending on circumstances.)

We received completed surveys from 237 relatives or other contact people from the initial mailing conducted during the summer of 1998. This represented a 36.5% response rate. This rate was not high enough in our judgement. We therefore sent out a second mailing to the families who did not respond to the first mailing. The second round was sent out in the fall of 1998. From the second round, we received an

additional 66 surveys. The total number of completed surveys from both mailings that were returned was 303. This represented a final overall response rate of 46.6%. This is exactly what we have come to anticipate in mail surveys of this kind. Over the past 20 years, we have surveyed tens of thousands of families of people with developmental disabilities, and we fairly consistently obtain a response rate just under 50%. The rate of 46.6% was therefore judged to be acceptable, and we moved into the analytical stage.

Instruments

The Hissom family survey form was derived from 20 years of our work surveying the families of people in institutions and communities. The first such surveys were conducted with families of people living at Temple University's Woodhaven Center in 1975. The Pennhurst Longitudinal Study's family surveys were the next generation of such studies, followed by work in Arizona, Arkansas, California, Connecticut, Colorado, Georgia, California, Indiana, Kansas, Massachusetts, New Hampshire, North Carolina, and Oklahoma.

The Hissom family survey was designed with one consistent question in mind: “Are the class members better off than they were at Hissom?” And if they are better off, then we want to know in what way(s), how much, and what did it cost?

The survey therefore included questions about beliefs, attitudes, memories of past attitudes, satisfaction, perceptions of qualities of life, perceptions of changes in qualities

of life, positive perceptions, negative perceptions, aspirations, and valued outcomes.

The instrument is included here as Appendix A.

Participants

The respondents to this survey were most often mothers, followed by mother and father responding together, then siblings, as shown in Table 1.

Table 1
Relationships of Respondents to the Former Hissom Residents

<u>Relationship</u>	<u>Number</u>	<u>Percent</u>
Mother	167	55.5%
Mother And Father	62	20.6%
Sister Or Brother	28	9.3%
Father	23	7.6%
Other Relative	19	6.3%
Unrelated Guardian	6	2.0%
Total	299	99.3%
Left Blank	2	0.7%

Most of the family respondents reported themselves to be full legal guardians of the Hissom class members, as shown in Table 2.

Table 2
Legal Relationship of Respondent to the Class Members

<u>Legal Status</u>	<u>Number</u>	<u>Percent</u>
Full Legal Guardian	229	76.1%
Limited Legal Guardian	27	9.0%
Legal Conservator	11	3.7%
No	26	8.6%
Total	293	97.3%
Left Blank	8	2.7%

The ages of the responding relatives ranged from 26 to 90, with an average of 62 years. They reported that the Hissom class members had lived at Hissom for time spans ranging from 3 months to 42 years, with an average of 12 years.

The ages of the class members ranged from 21 to 58, with an average of 37. The class members were 56% male and 44% female. They bore labels as follows: 14% mild, 19% moderate, 23% severe, 40% profound, and 4% unknown. Ethnicity broke down as 89% European-American, 9% African-American, 3% American Indian, and 1% Other.

The survey asked the responding families what kind of homes the Hissom class members were living in. Table 3 shows their responses. More than 50% said their Hissom relatives had moved to supported living situations, and another 13% said group homes, and 14% were in their own home or apartment. It should be kept in mind that parents and other relatives may not use terminology and jargon in the same way as do professionals.

Table 3
Types of Homes Hissom People Are Living In, As Reported by Relatives

<u>Type of Home</u>	<u>Number</u>	<u>Percent</u>
1 Group Home	40	13.3%
2 Adult Foster Care	13	4.3%
3 Here With Us	20	6.6%
4 With Other Relatives	1	0.3%
5 Own Apt/Home	41	13.6%
6 Supported Living Home	153	50.8%
7 Independent Living	6	2.0%
8 Some Other Kind Of Home	7	2.3%
9 Nursing Home	5	1.7%
10 Mental Health Institution	2	0.7%
11 Other	5	1.7%
Total	293	97.3%
Left Blank	8	2.7%

Table 4 describes the contacts between family and person during the preceding year. Telephone was the most frequent method, at about 82 times per year, or just under 7 times a month. Visits to the person at his community home were also fairly frequent, at 34 per year, or almost 3 per month.

Table 4
Types and Amounts of Contact Between Family and Person

<u>Type of Contact</u>	<u>Average Number of Times Per Year</u>	<u>Range</u>
Telephone Calls	82	0 to 500
Mail	4	0 to 300
Visited At His/Her Home	34	0 to 365
Took For An Outing	16	0 to 365
Program Planning Meetings	4	0 to 203
Consent For Medical Care	2	0 to 50

The person was picked up by family members and taken on an outing just over once a month. This group of families attended an average of 4 program planning meetings a year, and gave consent for medical care an average of twice a year.

Results

The first question about the move from institution to community was: “(8) When you first heard about the idea for your relative/ward to move to a new home in a regular residential neighborhood, were you ‘for’ it or ‘against’ it?” The responses showed a wide range of recalled feelings, as shown in Table 5.

Table 5
Initial Family Feelings About Move to Community

<u>Attitude</u>	<u>Number</u>	<u>Percent</u>
Strongly Against	48	15.9%
Against	68	22.6%
In Between	59	19.6%
In Favor	49	16.3%
Strongly In Favor	69	22.9%
Total	293	97.3%
Left Blank	8	2.7%

Initial attitudes were almost equally distributed on the positive and negative sides of the issue.

The next question was intended to test for change in attitudes: “(9) How do you like your relative’s/ward’s new home?” Current attitudes are markedly different from initial attitudes, as shown in Table 6.

Table 6
How do you like your relative's new home?

<u>Attitude</u>	<u>Number</u>	<u>Percent</u>	<u>Adjusted Percent</u>
Not At All	2	0.7%	0.7%
Very Little	1	0.3%	0.4%
Somewhat	26	8.6%	9.3%
Very	113	37.5%	40.4%
Extremely	138	45.8%	49.3%
Total	280	93.0%	
Don't Know	3	1.0%	
Left Blank	18	6.0%	

The pattern is extraordinary. Among these 301 families, 277 express some level of positive feeling, that is, they say they feel somewhat, very, or extremely positive. If we take out the families said “Don’t Know,” or who left this item blank from the percentages, we see that the figure for some degree of positive feelings is 98.9%.

In our research over the years, we have become accustomed to very positive family feelings about community living. However these results are the most positive we have ever seen. This is in keeping with the fact that, overall, the positive outcomes of deinstitutionalization in Oklahoma have been the most compelling this research team has ever seen (Conroy, 1999).

To further illustrate the magnitude of the changes in family attitudes, we can crosstabulate the two questions, to see how many families first felt negative, and now feel positive.

Table 7
“Before and After” Family Attitudes About Community Living

		AFTER				
B E F O R E		Strongly Against	Against	In Between	In Favor	Strongly In Favor
	Strongly Against	2	0	6	19	18
	Against	0	0	8	31	24
	In Between	0	0	3	32	22
	In Favor	0	1	2	16	28
	Strongly In Favor	0	0	7	14	46

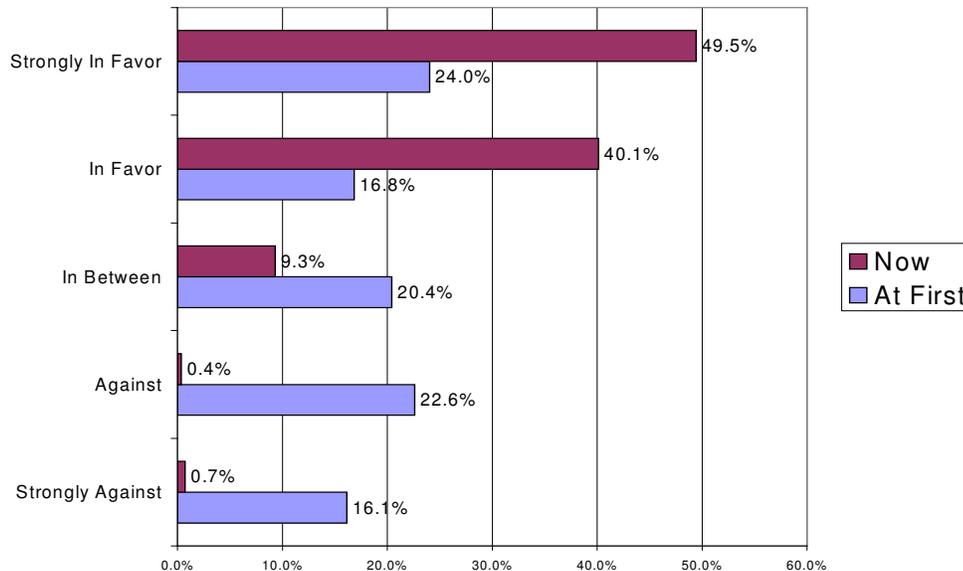
Table 7 shows the number of families with each possible mixture of “before and after” attitudes. The most remarkable entries in the table are at the top right. There are 18 families who were strongly against the move, and now are strongly in favor. All the entries toward the upper right of the table represent families who changed their opinions in a positive direction. It is worth noting that only 1 family changed from “in favor” to “against.” Some of the information in the table may be clearer in percentage format.

Table 8
“Before and After” Family Attitudes About Community Living
In Percentage Format

		AFTER					
B E F O R E		Strongly Against	Against	In Between	In Favor	Strongly In Favor	
	Strongly Against	0.7%	0.0%	2.2%	6.8%	6.5%	16.1%
	Against	0.0%	0.0%	2.9%	11.1%	8.6%	22.6%
	In Between	0.0%	0.0%	1.1%	11.5%	7.9%	20.4%
	In Favor	0.0%	0.4%	0.7%	5.7%	10.0%	16.8%
	Strongly In Favor	0.0%	0.0%	2.5%	5.0%	16.5%	24.0%
		0.7%	0.4%	9.3%	40.1%	49.5%	100.0%

In this format, it is easy to see the drastic change in family attitudes. At the lower left, we can see that a total of only 1.1% of families (0.7%+0.4%) are currently opposed to community living for their relatives. At the upper right, we can see that when the judge handed down his decision, 38.7% of the Hissom families were opposed to movement to the community – about the same percentage as were in favor. Now the families are about 90% in favor, with another 9% “in between.” A visual presentation of these findings is given in Figure 1.

Figure 1
Initial and Current Attitudes About Community Living



These are certainly dramatic findings. We set out to learn about the feelings of these families many years after the closure. These data provide a compellingly clear answer. They are overwhelmingly supportive of the change, even though many felt the opposite at first.

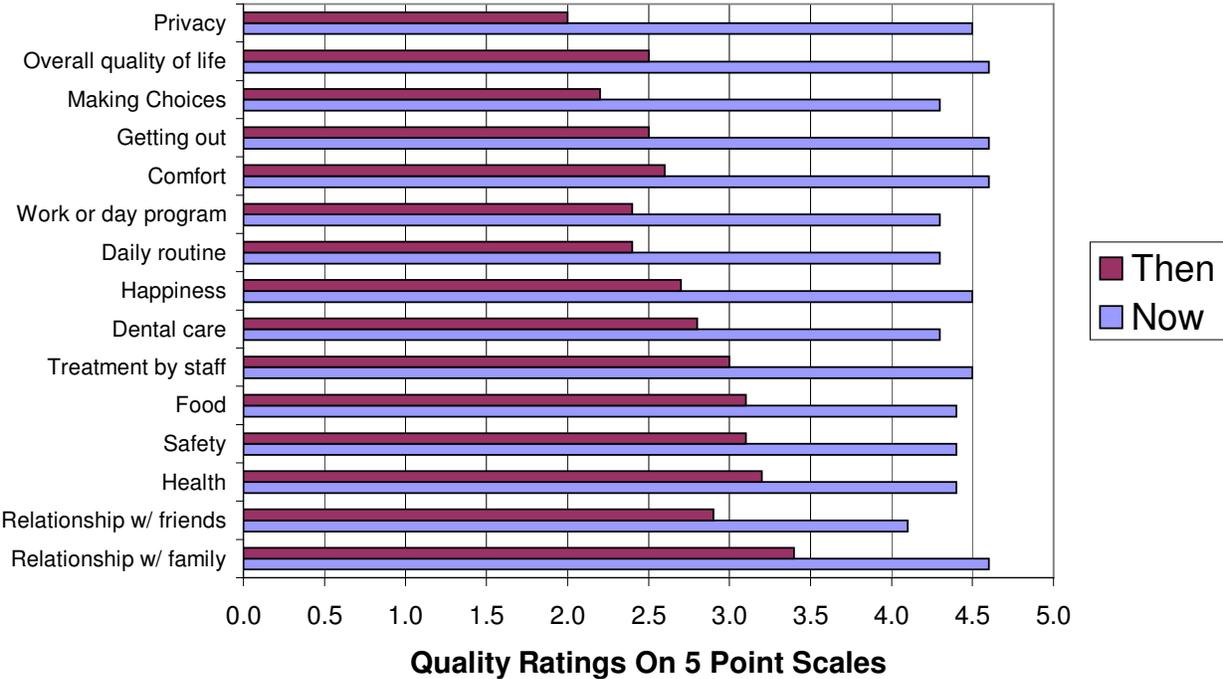
The next question on the survey (as can be seen on Page 3 of Appendix A, item number 13) was a table of ratings of qualities of life. The table was set up to obtain ratings of life qualities “Then and Now.” “Then” meant when the class member was at Hissom, and “Now” meant currently, in the community. We asked families to give ratings on a 5 point scale, from “Very Poor” to “Very Good.” Areas of quality of life included relationships with family, relationships with friends, safety, happiness, health,

dental care, and making choices. The responses on this question should be thought of as perceptions of qualities of life. They are not true “measurements” of quality, but rather they represent what the families believe to be true, “Then and Now.”

We have summarized the results in graphic form in Figure 2. Every one of the differences between “Then and Now” was statistically significant beyond $p = .001$. This means that such a large difference could have occurred by chance alone, but this would happen less than 1 time in 1,000. In other words, these differences are almost certainly real.

Figure 2

**Perceived Changes in Qualities of Life:
1999 Survey of Hissom Class Member Families**



The lighter bars represent family ratings of qualities of life for the class members “Now.” The darker bars represent the families’ estimates of what quality was like “Then,” back at the Hissom Memorial Center. Every light bar is much larger than its corresponding dark bar. This means the families feel, on the average, that their relatives are “better off” in every way on these 15 quality of life dimensions.

We sorted the bars in the graph above so that the one at the top shows the quality dimension that showed the largest increase from “Then” to “Now.” It is intriguing and instructive to note where the largest gains occurred. The first was Privacy, suggesting that families saw a sharp contrast between the congregate care setting and the community supported living settings in regard to individual privacy. This may be related to one of the common comments people themselves make about the greatest differences between institution and community living: less noise. Group living tends to be associated with constant clamor, noise, and the rarity of ever being alone. The contrast is difficult for us to imagine. Most of the class members now have their own bedrooms, and they have the freedom to be alone when they want to.

The second largest gain was in “Overall Quality of Life.” It is abundantly clear that families see their relatives as “better off” in their community homes.

The third largest change was in “Making Choices.” It seems clear that the families have come to the conclusion that their sons and daughters, brothers and sisters, are not incapable of taking some control over their lives. The fact that they had no control whatsoever while at Hissom, and now their parents say the third largest change

in their lives has been in “Making Choices,” seems to us to be extremely relevant to the self-determination movement (Conroy & Yuskas, 1996).

The smallest changes were in Health, Relationships with Friends, and Relationships with Family. The Health finding is important, since health is one of the strongest concerns of families (see the analysis of valued outcomes below). Families told us that their relatives’ health changed for the better, but the change was small compared to the other great changes. The Relationships finding is interesting. It suggests that families perceive that their relatives had good relationships while at Hissom, and those relationships are now better, but not as much improved as in all the other areas of quality.

To further test the findings about perceived quality of life, we “added up” the scores on all 15 dimensions of quality, and made a new scale that ranges from 0 to 100. A score of 100 would mean that the families rated the person’s life as the highest possible level in every area. A score of 0 would mean that the person’s life was the lowest possible quality in every area.

We have been using this “Quality of Life Changes” scale for many years. We have used it to track changes in perceived quality for thousands of deinstitutionalized people, for thousands of people becoming involved in self-determination, for thousands of children in foster care. We have never seen a difference of this magnitude:

Then	Now	Significance
43.8	85.5	.0001

The “Now” score is just below double the “Then” score. We are accustomed to seeing 10, or even 20-point changes, on this scale. We have never seen a score double from “Then” to “Now.”

The largest increase we have seen in the past is for several hundred people who recently moved out of institutions in Indiana. Their Quality of Life Changes scores increased from 50 to 78. Interestingly, Indiana followed Oklahoma’s lead in providing supported living situations rather than group homes.

There can be little doubt of the fact that Oklahoma’s Hissom families are happy with the move from institution to community. Even those families that opposed the change are now convinced that it was wise to make the change.

To illustrate the conclusion, we have randomly selected family comments in response to the question, “*What is the biggest change your relative has experienced since leaving Hissom?*” We used the computer to select 50 comments completely at random, and we reproduce those comments here. Some of the families left this item blank, so the list below has fewer than 50 comments. We have alphabetized the comments, so that any general commonalities can be more easily identified.

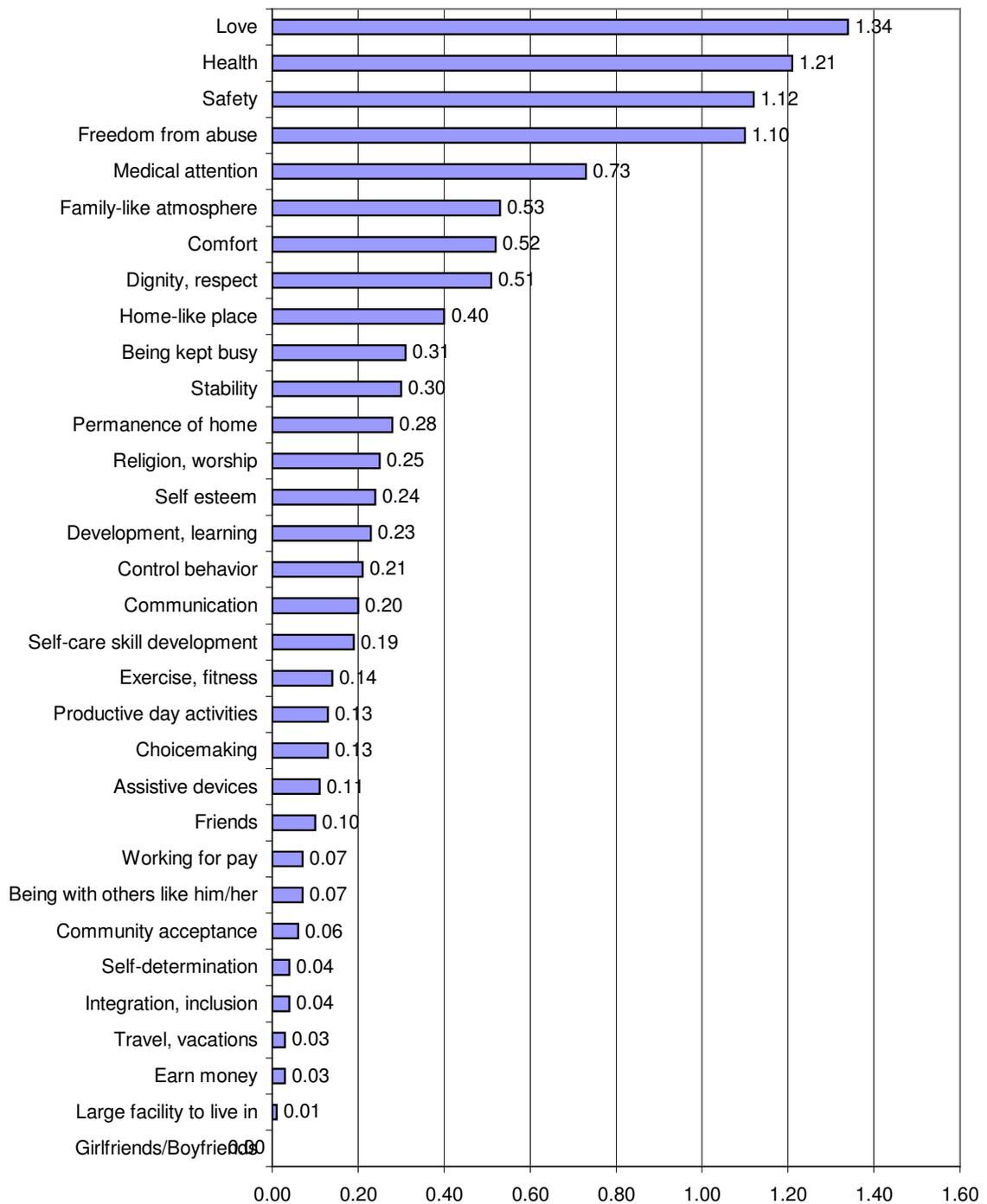
Responses to “What is the biggest change your relative has experienced since leaving Hissom?”

- Adjustment to freedom
- Atmosphere
- Being and working with the public
- Can walk instead of being confined
- Choices not always right
- Closer to medical facilities
- Express more freely
- Finding out all agencies are not the same
- Freedom
- Happiness, freedom, love
- He gets to do more things he wants to do
- He is more productive and earns own spending money
- Her ability to communicate
- He's always happy
- He's learned how to love again
- His move from a nursing home to the present form of living
- His self esteem / tries to do everything they ask him to do
- Improved health
- Independence
- Independence she has now
- Learned new job skills and new daily living skills
- Live close to family
- More independent and can communicate with me
- More independent in daily living
- More outgoing, not shy
- More personal care and supervision
- More satisfied
- More self confident
- Move into own home
- Out in community
- Personal growth / job
- Prove her accomplishments
- School to work
- Self esteem
- Self-esteem
- Self sufficient
- Some of her abilities
- Spent years at [name of facility] before going to supported living
- Suffered cardiac arrests
- Taking better care of self
- She can talk better and she enjoys work
- Treated like human being

On page 6 of the survey (Appendix A), we asked families to tell us what were the five most important things for their relatives' well being. This question was an attempt to get at what families value. What outcomes, what qualities of life, do families view as the most important?

The families rated their #1 concern by writing a "1" next to the most important quality dimension. Then they wrote a "2" next to the second most important consideration, and so on up to 5 items. The results are presented graphically in Figure 3.

Figure 3
Valued Outcomes Expressed by the Families



The most important valued quality of life expressed by these families was “Love.” The family respondents were parents more than 70% of the time, this is not surprising. All parents want this fundamental quality for their children. Health came next, and the same interpretation applied. However, the health question might have been related to the “medical model” under which their sons and daughters were initially committed to Hissom an average of 20 years ago.

Who advised these families to place their children at Hissom? Most often, the answer was “Physicians.” With all the best intentions, physicians told the families that their children were somehow “sick,” that they required constant medical attention, that they would bring no joy to the family unit, that they could only thrive and develop at a specialized facility like Hissom. Thus Hissom was described as the best the children could ever hope for. And, at that time in American history, that was probably true.

Safety and freedom from abuse followed, and this was understandable as well. The fifth greatest concern was “Medical Attention,” and this was closely related to “Health.”

It is very interesting to see what is at the bottom of the family values hierarchy. Choicemaking is fairly low, and self-determination is even lower. Earning money is almost dismissed out of hand. Having Girlfriends/Boyfriends received not a single vote. Integration and inclusion mean almost nothing to these families. Community acceptance is not valued highly either, possibly because these families cannot even imagine their sons and daughters being active in any kind of community life.

Our interpretation of these “Valued Outcome” data is that the values of professionals in this field of work are quite disparate from the values of families. As our research continues, we suspect we will find that both family and professional value systems are markedly different from those of the people themselves. We will be exploring the theory that our differences in fundamental values is related to the intense conflicts, both in and out of court, that we have experienced during the past 30 years in America. When we understand our basic differences in values better, perhaps we can find solutions and compromises with less strife.

Conclusion and Future Work

The 1998-1999 Oklahoma Hissom Family Survey has provided a rich database. This first brief report is intended only to highlight the findings that are most relevant to the concerns of the Court and DHS. We believe the survey has proven that the Hissom families are extremely satisfied with Oklahoma's community supports. They are also glad that the change occurred. Although many families were wary of community at first, the vast majority is now in favor of community rather than institutional living.

In future reports, we will address the information in the Family Survey about:

- Day Programs (past analyses have shown that the Hissom class members are leading the nation in supported and competitive employment – are the families pleased with all this?);
- Family perceptions of Case Managers, including satisfaction, frequency of contact, and usefulness of the interactions;
- The families' review of the extent to which they were “kept informed” during the closure process, and their comments about that issue;
- Analysis of power and control and self-determination in the eyes of the families.

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Appendix A: Family Survey Instrument

**1998 SURVEY OF FAMILIES AND GUARDIANS
OF PEOPLE WHO ONCE LIVED
AT HISSOM MEMORIAL CENTER**

Dear Relative or Guardian:

This is a survey of the families and guardians of people who once lived at Hissom Memorial Center near Tulsa.

The Oklahoma Department of Human Services would like to find out about your opinions. The Department has asked us to write to you and send you a survey, so that we can find out what you think. We want to know if you think your relative is better off, worse off, or about the same, since leaving Hissom, and in what ways. We also want to know whether you think the services being provided to your relative are good, bad, or indifferent. We want to hear whatever else you might have to say about your relative's situation. Your answers will be kept confidential, UNLESS you tell us differently on the last question in the survey.

The questions in the survey work like this:

(1) How happy are you with?

Very Unhappy	Unhappy	In Between	Happy	Very Happy	Don't Know
1	2	3	4	5	9

Choose the word that best describes your answer to the specific question and then circle the number that appears underneath that word. For example, if your answer is "In Between", you would circle the number "3" that appears just below the answer "In Between." If your answer was "Happy" than you would circle the number "4" that appears below the word "Happy."

If there are questions that do not apply, or to which you don't know the answer, just leave them blank. The survey only takes about 10 minutes. Please be sure that your voice is heard.

Sincerely,

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(6) What kind of place does your relative live in now?

1. Group Home
2. Adult Foster Care/Adult Companion
3. Here With Us
4. With Other Relatives
5. Own Apartment/Home With Supports
6. Supported Living Home
7. Independent Living
8. Some other kind of home in the community

Please describe: _____

9. Nursing Home

10. Mental Health Institution

11. Other:

Please describe: _____

(7) **About** how many contacts of each kind in the past year have you had with your relative?

(If your answer to question 6 was “3 – Here with us,” some of the items below may not be applicable and should be answered “0”.)

About how often in the past year? (Zero if none)	Type of Contact
	7a. Telephone calls
	7b. Mail
	7c. I (we) visited him/her at his/her home
	7d. I (we) took him/her for an outing, or to our home
	7e. Program Planning Meetings
	7f. Consent for medical care

(8) When you first heard about the idea for your relative to move to a new home in a regular residential neighborhood, were you "for" it or "against" it?

Strongly Against	Against	In Between	In Favor	Strongly In Favor
1	2	3	4	5

(9) How do you like your relative's new home?

Not at all	Very little	Somewhat	Very	Extremely	Don't Know
1	2	3	4	5	9

(10) How happy do you think your relative is with his/her current living situation?

Very Unhappy	Unhappy	In Between	Happy	Very Happy	Don't Know
1	2	3	4	5	9

(11) How happy are you with your relative's current living situation?

Very Unhappy	Unhappy	In Between	Happy	Very Happy	Don't Know
1	2	3	4	5	9

(12) Would you recommend to other families that they make the change in living situation from an institution to a home and service support in the community?

Yes, Definitely	Yes, Probably	In Between	No, Probably Not	No, Definitely Not
1	2	3	4	5

(13) QUALITIES OF LIFE, THEN AND NOW

Please circle numbers to describe your opinions about the qualities of your relative's life **THEN**, when living at Hissom, and his/her qualities of life **NOW**, in a community home. For any items that you don't know, just don't circle anything. Please use the scale below to rate each area.

Very Poor	Poor	In Between	Good	Very Good
1	2	3	4	5

THEN: AT HISSOM	QUALITY AREA	NOW: IN COMMUNITY
1 2 3 4 5	10a. Relationship with family	1 2 3 4 5
1 2 3 4 5	10b. Relationship with friends	1 2 3 4 5
1 2 3 4 5	10c. Getting out and getting around	1 2 3 4 5
1 2 3 4 5	10d. What he or she does all day	1 2 3 4 5
1 2 3 4 5	10e. Safety	1 2 3 4 5
1 2 3 4 5	10f. Treatment by staff/attendants	1 2 3 4 5
1 2 3 4 5	10g. Food	1 2 3 4 5
1 2 3 4 5	10h. Happiness	1 2 3 4 5
1 2 3 4 5	10i. Health	1 2 3 4 5
1 2 3 4 5	10j. Dental care	1 2 3 4 5
1 2 3 4 5	10k. Making Choices	1 2 3 4 5
1 2 3 4 5	10l. Privacy	1 2 3 4 5
1 2 3 4 5	10m. Comfort	1 2 3 4 5
1 2 3 4 5	10n. Work or day program	1 2 3 4 5
1 2 3 4 5	10o. Overall quality of life	1 2 3 4 5

(14) How happy do you think your relative is with his/her day program or job, or whatever he/she does during the day?

Very Unhappy	Unhappy	In Between	Happy	Very Happy	Don't Know
1	2	3	4	5	9

(15) How happy are you with your relative's day program or job, or whatever he/she does during the day?

Very Unhappy	Unhappy	In Between	Happy	Very Happy	Don't Know
1	2	3	4	5	9

(16) Since the move to the community, about how many times has your relative changed homes? (Zero means no changes since moving to the community.)

_____ or ___ Don't Know

(17) Overall, how happy do you think your relative is now?

Very Unhappy	Unhappy	In Between	Happy	Very Happy	Don't Know
1	2	3	4	5	9

(18) Overall, do you think your relative's life is better today/now than when he or she lived at Hissom?

Yes, Definitely	Yes, Probably	In Between	No, Probably Not	No, Definitely Not
1	2	3	4	5

(19) Are you happier and more satisfied with the services your relative receives now while living in the community versus the services he or she received while living at Hissom?

Yes, Definitely	Yes, Probably	In Between	No, Probably Not	No, Definitely Not
1	2	3	4	5

(20) Do you know your relative's case manager or service coordinator?

1. Yes
2. No

(21) How satisfied are you with your relative's case manager or service coordinator?

Very Unhappy	Unhappy	In Between	Happy	Very Happy	Don't Know
1	2	3	4	5	9

(22) Since the move to the community, about how many times has your relative/ward had a change in his or her direct care staff and/or service provider?

1. About once a month or more
2. Between once a month and once every three months
3. Between once every three months and once every 6 months
4. Between once every six months and once a year
5. Once a year or less

(23) Looking back, how well were you kept informed about what was happening with your relative during planning for community placement?

1. Not At All: Always found out about things after they happened (if at all)
2. Very Little: Usually found out afterward
3. Somewhat: Sometimes knew, sometimes didn't
4. Well: Usually knew in advance what was happening
5. Very Well: Always informed in advance about what was being planned

(24) Do the supports/services received by your relative reflect your preferences about what she or he needs?

Yes, Definitely	Yes, Probably	In Between	No, Probably Not	No, Definitely Not
1	2	3	4	5

(25) Do the supports/services received by your relative reflect your relative's preferences about what she or he needs?

Yes, Definitely	Yes, Probably	In Between	No, Probably Not	No, Definitely Not
1	2	3	4	5

(26) Do you agree with your relative's preferences concerning supports and services?

Yes, Definitely	Yes, Probably	In Between	No, Probably Not	No, Definitely Not
1	2	3	4	5

(27) If you disagree with your relative's preferences, please explain why and in what areas:

(28) How much attention was given to your opinion about what was best for your relative during the movement from institution to community?

None	Very Little	Some	Significant	Major	Don't Know
1	2	3	4	5	9

(29) Were you satisfied with the amount of attention that was given to your opinion about what was best for your relative during the move from institution to community?

Yes, Definitely	Yes, Probably	In Between	No, Probably Not	No, Definitely Not
1	2	3	4	5

(30) Right now, how much input do you think your relative has in major decisions about his or her life, like where to live, with whom, what to do during the day, recreation, worship, and so forth?

None	Little	Some	A Lot	Most or All	Don't Know
1	2	3	4	5	9

(31) Right now, how satisfied are you with the amount of input your relative has regarding the major decisions in his or her life like where to live, with whom, what to do during the day, and so forth?

Not at all	Very little	Somewhat	Very	Extremely	Don't Know
1	2	3	4	5	9

(32) Right now, how much input do you have in major decisions about your relative's life, like where to live, with whom, what to do during the day, recreation, worship, and so forth,?

None	Little	Some	A Lot	Most or All	Don't Know
1	2	3	4	5	9

(33) Right now, how satisfied are you with the amount of input you have regarding the major decisions in your relative's life like where to live, with whom, what to do during the day, and so forth?

Not at all	Very little	Somewhat	Very	Extremely	Don't Know
1	2	3	4	5	9

(34) FIVE MOST IMPORTANT THINGS

In the section below we would like to know what the five most important things are to you and to your relative concerning his or her well-being. What is important to you may differ from what your relative thinks is important.

Part 1: Please read through the list below and determine which of these is the #1 most important thing to you about your relative's well-being? Please write a "1" next to that item. Then, please write a "2" next to the SECOND most important thing to you. Please continue writing numbers up to 5, for the fifth most important thing to you.

Part 2: Next, read through the list again and determine which of these is the #1 most important thing to your relative concerning his or her well-being. Write a "1" next to this item in the last column. Then, determine the second most important thing to your relative and write a "2" next to this item. Please continue writing numbers up to "5" for the fifth most important thing to your relative.

Important to You		Important to Your Relative
_____	Assistive devices	_____
_____	Being kept busy	_____
_____	Being with other people with disabilities	_____
_____	Choicemaking	_____
_____	Comfort	_____
_____	Communication	_____
_____	Community acceptance	_____
_____	Supports for problematic behavior	_____
_____	Development, learning	_____
_____	Dignity, respect	_____
_____	Earn money	_____
_____	Exercise, fitness	_____
_____	Family-like atmosphere	_____
_____	Freedom from abuse	_____
_____	Friends	_____
_____	Girlfriends/Boyfriends	_____
_____	Health	_____
_____	Home-like place	_____
_____	Integration, inclusion	_____
_____	Large facility to live in	_____
_____	Love	_____
_____	Medical attention	_____
_____	Permanence of home	_____
_____	Productive day activities	_____
_____	Religion, worship	_____
_____	Safety	_____
_____	Self esteem	_____
_____	Self-care skill development	_____
_____	Self-determination	_____
_____	Stability	_____
_____	Travel, vacations	_____
_____	Working for pay	_____

(35) How satisfied are you with the degree to which these five “most important things” have been attained and/or accomplished?

Not at all	Very little	Somewhat	Very	Extremely	Don't Know
1	2	3	4	5	9

(36) How satisfied is your relative with the degree to which these five “most important things” have been attained and/or accomplished?

Not at all	Very little	Somewhat	Very	Extremely	Don't Know
1	2	3	4	5	9

POSITIVES AND NEGATIVES

(37) Please list one or more things that you like about your relative's current situation.

(38) Please list one or more things that you are most concerned about with regard to your relative's current situation.

(39) What is the biggest change your relative has experienced since leaving Hissom?

(40) If you had one wish for your relative, what would it be?

(41) Is there anything you would like to say about your relative's situation?

(42) Your answers can be kept completely confidential, or if you wish, we can tell officials exactly who you are and what you said.

1. Keep confidential
2. Tell them what I said

THANK YOU!