

***Governor's Council on Disabilities and Special Education***  
Creating change that improves the lives of people with disabilities.

**A Study of the Impact of  
Deinstitutionalization  
on the Former Residents of  
Harborview Developmental Center  
*August, 1998***



Department of Health and Social Services  
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## Executive Summary

Since its formation in the late 1970's, the Governor's Council on Disabilities and Special Education advocated for the transfer of people living at Harborview Developmental Center to community programs. The Council and other advocates maintained that community services cost less than institutional care, the quality of life of people is better in the community, and the community based services system had the resources to provide support to Harborview residents. Now that Harborview has closed, the Council is conducting a study to determine whether the closure was in the best interest of the people who were living there.

The Harborview Study included interviews with former residents, a survey of family members and guardians, interviews with key informants, and an analysis of the economic impact of the transfer of Harborview Developmental Center residents to community programs. Major findings were:

- Between 1961, when Harborview opened, and 1997 when it closed, 344 people were admitted to the facility. The population at Harborview reached its peak in 1972 when 130 people lived there.
- Former residents, families/guardians and community service providers felt that the Division of Mental Health and Developmental Disabilities provided adequate support during the transition of Harborview residents to community programs. Former residents reported (77.8%) that they felt that their needs and wants were considered during the transition from HDC. All of the family members and guardians (100%) responding to the survey said that their views were considered during the transition process.
- While many family members or guardians were initially skeptical, most are now pleased with their family member's new lifestyle and the positive changes they have seen.
- Former residents and their guardians rated the former residents' quality of life highly in most areas. Areas that are problematic are employment and integration into the community.
- Former residents and guardians reported that community based services are meeting their wants and needs. Employment services are the greatest need. Most of former residents (77.8%) do not have jobs.
- The cost of care in the community (\$94,878, including Adult Public Assistance and Food Stamps) is significantly less than the costs at Harborview (\$164,000). The net saving equals \$69,122 per person.

The study also identified a number of system's issues:

- Most (77.3%) of the former HDC residents do not have jobs. Many others in community programs are also waiting for supported employment services. Without additional resources for employment services, this will continue to be an issue.
- There is still work to be done in providing consumers with real choices and integrating them into their communities. These are values that are widely held by community programs. They are also the values that are most difficult attain. While it is clear that programs are getting former residents out into the community, the challenge will be to support consumers in establishing individual relationships.
- Staff turnover negatively impacts family and guardian confidence in community services. Low wages and lack of benefits cause high turnover and a perceived lack of consistent and professional care.

## Introduction

In the mid-1990s, the Alaska Department of Health and Social Services made the decision to phase out Harborview Developmental Center (HDC). The three-year closure plan was the collaborative effort of many state and community agencies. These included the Alaska State Legislature, the Governor's Council on Disabilities and Special Education, the Alaska Developmental Disabilities Providers Association, the Disability Law Center and consumer advocates, consumers and families, the Alaska Mental Health Trust Authority, the Department of Health and Social Services, and Division of Mental Health and Developmental Disabilities (DMHDD).

Harborview Developmental Center closed its doors on November 15, 1997 after 36 years as the only state-run institution for Alaskans with developmental disabilities. People who had spent much of their lives at Harborview Developmental Center are now living in small group homes, their own supervised apartments or, for some of the older individuals, in nursing homes.

Since its formation in the late 1970's, the Governor's Council on Disabilities and Special Education advocated for the transfer of people living at Harborview Developmental Center to community programs. The council and other advocates maintained that community services cost less than institutional care, the quality of life of people is better in the community, and the community based services system had the resources to provide support to Harborview residents. Now that Harborview has finally closed, the Council is conducting a study to test these assumptions and to determine how those who left Harborview in the past ten years are faring in the community.

The central question explored in the study is whether the closure of Harborview Developmental Center was in the best interest of the people who were living there. A number of issues relating to the closure are explored in this report. They include the:

- transition process from HDC to the community for former residents, families and guardians and community service providers
- quality of life of former HDC residents in the community
- capacity of the community services system to meet the needs of former HDC residents
- permanence of community services
- economic impact of the HDC closure

## Study Methodology

Information Insights used a number of research methods to gather information for this report. Interviews were conducted with former residents and key informants, and family members or guardians of former residents received a mail-in questionnaire. The key informants included representatives from the Division of Mental Health and Developmental Disabilities and other state agencies involved in the closure, community services providers, and advocates.

Information on the cost of services at HDC and in the community was gathered from the Department of Health and Social Services. The Division of Mental Health and Developmental Disabilities provided a list of all those admitted to Harborview since it opened in the 1960s.

The project sample was limited to those discharged from Harborview in the past ten years. Because Information Insights could not contact former residents and family/guardians directly, community programs provided assistance by sending out surveys and interview interest/permission forms for the former residents for whom they provide services and supports. Of the 99 people discharged from Harborview between January 1, 1987 and November 15, 1997, 18 had died and 12 could not be located. According to DMHDD records and subsequent follow-up by Information Insights, it was determined that former residents of HDC were discharged to and/or are currently receiving services from the following agencies:

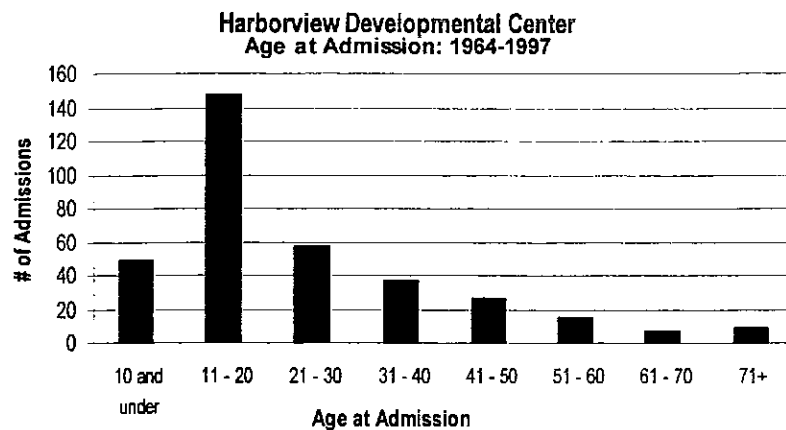
Alaska Psychiatric Institute	Anchorage
Anchorage Pioneer's Home	Anchorage
ARCA	Anchorage
ASETS	Anchorage
Bethel Community Services	Bethel
Community Connections	Ketchikan
Deaf Community Services,	Fairbanks
Denali Center Nursing Home	Fairbanks
Fairbanks Resource Agency	Fairbanks
Frontier Community Services	Soldotna
Hope Cottages	Anchorage
Horizons Unlimited	Valdez
Ketchikan Pioneer's Home	Ketchikan
Kodiak Island Mental Health Center	Kodiak
Mat-Su Services for Children and Adults	Wasilla
Our Lady of Compassion Care Center	Anchorage
Assisted Living Homes	Anchorage
Foster Homes	Anchorage/Valdez

Information Insights interviewed 22 former residents and 16 key informants, and received completed surveys from 18 family members or guardians of former residents.

## The People Who Lived at Harborview Developmental Center

Harborview opened in 1961 as the state's institution for people with developmental disabilities. Prior to this time, any child or adult needing more care than their family could provide were sent to Morningside Hospital and Baby Louise Haven in Oregon. Alaska offered no community care, even for people with less severe disabilities. The 1964 Good Friday earthquake destroyed the original Harborview along with the rest of the community of Valdez. The current Harborview Developmental Center facility was constructed with federal assistance after the earthquake.

Between 1964 and 1997, 344 people were admitted to Harborview Developmental Center. Harborview was at its peak in 1972 when it housed 130 residents. Of the 344 people who lived at HDC over the years, 236 (69%) were male and 108 (31%) were female. More than half (57%) of those admitted were 19 or younger.



Harborview served primarily as a facility for children and young adults with developmental disabilities during the first two decades of existence. The average age of those admitted through 1986 was 19.0 years. This group of HDC residents spent an average of 19.1 years living at the Valdez facility.

By 1986, the number of people with developmental disabilities living at HDC was dropping as programs were developed in the community. In August 1986, the Sourdough Unit was opened to serve people who had behavioral problems that made placement at other facilities, in particular nursing homes, difficult. These individuals were generally older than the rest of the Harborview population. Few individuals experiencing developmental disabilities were admitted to HDC after the mid 1980s. The average age of those admitted after August 1986 was 49.7 years.

**Harborview Developmental Center  
Age at Admission/Discharge, Length of Stay**

	Age at Admission	Age at Discharge	Years at Harborview
All Harborview Residents (1964-1997)	31.4	45.4	13.7
Before Sourdough Unit (1964 - 1986)	19.0	38.0	19.1
After Sourdough Unit (8/86 - 11/97)	49.7	54.0	4.2

## Transition from Harborview to the Community

Former HDC residents, families/guardians and key informants were generally positive in their views and comments about state support of the transition process from HDC to the community. While 83.3% of the family/guardian survey respondents said that they received adequate support during the transition of their family member, some of them reported that there were problems experienced along the way.

- Harborview provided a safe, familiar home for XXXX since 1974. It was a shock to accept any change and it came on us suddenly. Probably no amount of time could have adequately prepared us.
- I was apprehensive that Harborview closing seemed to be moving rapidly in spite of public opinion. Control seemingly rested only in administrative hands.
- We had no say, was just told what would happen. We were very pleased with progress and chances to try new things.

Many families/guardians made positive comments as well.

- We noticed XXXX didn't bring all his toys with him. Probably lost in HDC. Lynn George, of Assets, was the most supportive person we have ever dealt with. She was sensitive, paid attention to detail, and got things done.
- I was at Harborview for conferences over the years that the change was taking place. I also had letters and telephone conversations. They knew I wanted him to stay at Harborview as long as possible.
- There were a number of meetings at ARCA to inform parents and legal guardians of the progress of the transition.
- Harborview kept in touch with us, letting us know when and how he would be transferred to Anchorage.
- I had telephone conferences with the Harborview staff. The Anchorage staff brought my husband and I into Anchorage during the planning stages.

State agency representatives, service providers and advocates interviewed for the key informant survey also said that they thought that the state had provided adequate support (85.7%) to former residents and guardians during the transition process.

- I believe so. It really was a leap of faith that services would be there and be better.
- The transition went well for consumers at HDC—but Alaska has a long way to go in providing community services.
- A cynical yes, but supports set expectations that it would continue at the same level permanently. Families thought they would be getting everything they needed but this was not always the reality.
- Support was very positive from our view—families were able to choose the home. They were very happy to get all the help they did.
- Absolutely, especially during the last phase—the supports needed varies. The State did an extraordinary job of supporting people with all of their needs.
- Yes, very adequate supports. DMHDD was very supportive in reviewing needs and wants and assisting with funding.
- Our consumers had public guardians and got lots of support from DMHDD and HDC staff. They gave us information and tips, our staff was able to spend time at HDC prior to the transition. They gave us behavior management ideas for clients as well.

Former residents reported (77.8%) that they felt that their needs and wants were considered during the transition from HDC. At the same time, 100% of family and guardian respondents said that their views were considered during the transition process.

### **Quality of Life in the Community**

One of the most frequently heard reasons for closing Harborview was that services in smaller community based programs would improve the quality of life for those living at HDC. While 'quality of life' is difficult to define and often the subject of heated debate, for the purposes of this study 'quality of life' includes integration into the family and community, and choice and self-determination. Former residents were asked a number of questions about their lives since they moved to community programs. Their family members/guardians were asked the same questions about their family member's life.

Former residents and their families/guardians reported that they are getting most of the services and supports they need to live in the community. However, there are a few indicators that will require continued attention by community programs. These are in the areas of choice (who you live with, what you do most days) and integration (into the neighborhood, having friends visit). It is also clear from the interviews and survey responses that community programs are working to integrate former residents into their communities (doing fun things in the community, participating in the community, transportation), this is an extremely difficult task and one with which all community programs struggle.

### **Quality of Life in the Community**

<b>Quality of Life Indicator</b>	<b>Response</b>	<b>Former Residents</b>	<b>Family/Guardians</b>
When goals are set for you do people...	Help you reach them	95.5%	80.0%
Feel safe in your neighborhood?	Very safe	81.8%	58.8%
Do you do fun things in the community?	Yes	72.7%	64.7%
Are you happy with where you live?	Very happy	68.2%	64.7%
Do staff help you be part of your community?	Yes	68.2%	66.7%
Transportation if you want to go somewhere?	Most of the time	68.2%	93.3%
Do you get the services you need?	Yes	63.6%	82.3%
Do you feel lonely?	No, not often	59.1%	69.2%
Feel like an important part of your family?	Yes	45.5%	58.3%
How do your neighbors treat you?	Very good	40.9%	42.9%
Choice in job/what you do most days?	Yes	35.0%	38.5%
Do you have a job?	Yes	22.7%	25.0%
Choice in who you live with?	A lot	18.2%	28.6%
Do friends come over to visit your home?	Often	9.1%	15.4%

Key informants were asked if the closure had a positive or negative impact on the lives of the former residents if the facility. None of the key informants said that the impact was negative (75% said it was positive).

### Impact of Transfer of HDC Residents to Community

	#	%
Positive	12	75.0%
Negative	0	0
Both	2	12.5%
Uncertain	2	12.5%
N/A or No Response	1	---

The key informants provided the following comments:

- Institutions like HDC are completely protected/artificial. They rob people of the richness of community and being integrated into a community. They need to be closer to the "American Dream." They are more likely to get caught up in it and make it true for themselves if they can see it. Living in the community means opportunities to work, families, volunteer in community, recreational opportunities, to be neighbors and friends with people who are not PAID to be there!
- A whole world opened to them now that hadn't before—they have more choices and freedom.
- They used to say that they will only eat certain foods—but here, they get to be involved with choosing what they eat. They are more interested and take an active part in the preparation of food and have increased appetites.
- HDC didn't feel "homey" at all—not anything like the Pioneer Home environment. It is much less restrictive here, people can do more for themselves—they are able to get own food and snacks in their own kitchen.
- Care at HDC was based on a medical model and the Pioneer Homes are based on social model approach—supporting people in what they can do in a "home like" environment. There was a very positive impact—people with dementia tend to do better in a homelike environment.
- Absolutely. You have to be there to see it. Joy, family reunification in some instances, better health, more engaged in community (having block parties - you don't get that in an institution).
- Like any decision that effects so many, there will be positive and negative effects. The changes I've seen are very positive. There is a small percentage who may do better in a different setting but its not fair to say all are doing perfectly well.

Key informants were also asked to provide examples of how a former resident's life has improved since discharge.

- A Valdez group home manager reported how much people's lives have changed, from sitting in a corner eating cookies at HDC to having their own kitchen. Now when they need a snack they can not only choose what it will be but go and get it independently. Now, these people have something to look forward to.
- One person was able for the first time to visit family members in California. A Kenai consumer had refused to move a trunk of his clothes into his room at HDC, but when he moved into a new community based home, he said, "now I can move my stuff in—because I have a room."
- Mental health consumers are more lively, socialization is more open and people are actively participating in culturally appropriate activities—like sewing fur, fishing (fish camp in summer and ice fishing in winter).
- I've had the opportunity to follow the lives of 5 people. In every case, their health is better, they are doing more, are more active and more productive in terms of functioning level. In 3 of those 5, the families are very happy with the quality of life of their family member.



- In some of the people, there was never a spark in their eyes while at HDC—now they laugh and smile!
- The majority of the people we support were at HDC at some time. Now, if someone is hungry or thirsty they can go into the kitchen and get some food and water. At HDC, they had to wait for these things to be offered first. There have been great improvements, especially with the lower functioning folks.
- Two former residents were amazed they could shut door to their bedrooms. They enjoy having privacy and a choice of churches to attend, and are doing more personal care willingly because they want to look good.

### **Community Services System Capacity**

Former residents and their families/guardians were asked to rate how well the community service system is able to provide the services and supports they need or want. While there is considerable variation between how former residents and family members/guardians rate services, both groups reported that most community services are meeting the needs of former residents well or extremely well. The service that appears to be the most problematic is employment.

More than 90% of the former residents interviewed said their nutritional needs were being met well to extremely well in the community. Other highly rated community services were mental health services (83.4%), community living services (81.8%) and health and medical services (77.2%). Education (37.5%) and employment (25%) services were the lowest rated services. This is not surprising since only 23% of the former residents interviewed have jobs.

Families and guardians were also asked to rate how well community services were meeting the needs of their family members. Behavioral support was the highest rated community service, with 90% of families and guardians saying that community services were meeting the behavioral support needs of their family members well/extremely well. Families and guardians also rated health and medical (84.6%), recreation/leisure (78.6%), nutrition (77.0%), community living (76.9%) and transportation services (71.4%) highly. Families and guardians reported that education services were the least likely to meet their family member's needs well/extremely well. Employment (60.0%), mental health services (55.5%), and education (37.5%), were less likely to be rated as meeting the needs of family members well/extremely well. More than half of the family members/guardian survey respondents did not know if these services were being provided or chose not to answer the question on the survey.

<b>COMMUNITY SERVICES</b>	<b>Former Residents</b>	<b>Family/Guardian</b>
Nutrition	90.8%	77.0%
Mental Health Services	83.4%	55.5%
Community Living Services	81.8%	76.9%
Health/Medical Care	77.2%	84.6%
Transportation	64.3%	71.4%
Recreation/Leisure	60.0%	78.6%
Behavioral Support	54.6%	90.0%
Education	37.5%	37.5%
Employment	25.0%	60.0%

The majority (63.6%) of former residents said that they are receiving the services they need. The services and supports they need but don't have include dental/medical services, physical therapy, recreation, and environmental modifications.

Former residents and family members/guardians are in agreement that former resident's lives have improved since moving to community services. More than seventy percent of former residents (77.3%) reported that their lives have improved since leaving Harborview. While many family members/guardians provided positive comments about care at Harborview, they also reported that the lives of former HDC residents have improved (71.4%) since moving into community services.

### Has Life Improved in the Community?

FORMER RESIDENT'S LIFE?	Former Residents	Family/Guardian
Improved	77.3%	71.4%
Stayed the same	18.2%	21.4%
Gotten worse	4.5%	7.1%

Comments about the change in former resident's lives from families/guardians include:

- Institutions are like a parallel universe. Life and institutions like HDC are apples and marbles. HDC was an eddy in the river of life-a stagnant eddy, a holding pattern in the flight of life.
- XXXX seems happier, smiles more at Eagle House.
- The environment of a home rather than an institution has improved the quality of her life.
- She is getting good care now, but XXXX and everyone was especially treated like family at Harborview.
- His needs are taken care of and he is also taken to movies and dinner or lunch every so often and he sees a doctor at Alaska Native Medical Center, he is happier.
- XXXX's care providers have changed numerous times since moving to ARCA. I believe 5 to date. Of these 5, 2 related well to XXXX and she was obviously well cared for healthy and happy!
- I'm putting improved because he's doing so well, but I really don't know that much about Harborview because we never went there to visit.
- More 1 on 1 attention by his care givers. More opportunities to go out on drives and out in the community.
- XXXX likes his privacy and is much more relaxed in his new home situation.
- We are unable to monitor foster home for abuse potential. We could always drop in at HDC any time. Not able to discover how much "nothing" time XXXX has at his home. We believe mental stimulation is important. However, his teeth are cleaned well.

## The Permanence of Community Programs

One of the greatest fears expressed by family members as the closure of Harborview approached was that funding of community service programs provided less permanence for their family member than a facility directly operated by the state. In order to explore this issue, family members and guardians were asked if they thought community programs or institutions like Harborview provide greater permanence for people with developmental disabilities. Even with the closure of HDC, 54.5% of those responding said that they believed that institutions provided more permanence than community programs.

### Perception of Permanence

	#	%
Community programs	5	45.5%
Institutions	6	54.5%
No Response	7	---

It is clear from most of the comments received that families and guardians had great confidence in the Harborview staff and the care their family members received there. Families and guardians said that the HDC staff provided a warm and caring environment. Among their comments were:

- As long as they are like Harborview. It never did have an "institutional" feeling-more like a combination of resort and large home. The small town is another reason that it was so successful. The community was so involved with Harborview, and Harborview with the community.
- I never did consider Harborview an institution, because of the excellent treatment by staff and a wonderful doctor there. Also the whole community took pride in the people staying at Harborview.
- So far I'm pleased with XXXX's community program, but I believe this answer could vary according to an individual's circumstances and the verdict could still be out. Financial permanence is hopefully not at risk as well.

While the closure of HDC demonstrated that state operated institutions do not guarantee life long care, the responses from families/guardian brought forward an important issue. From the family/guardian perspective, permanence is not only a guarantee of funding, but permanence of providers. One of the positive aspects of HDC was that many of the care providers had worked there for years. HDC staff got to know HDC residents and their families on a long-term basis.

The staff at Harborview did not change often because, as state employees, their jobs offered good wages and benefit and retirement programs. Community program staff in comparable positions make significantly less, and often have minimal benefit and retirement packages. This has meant that care givers change more frequently in community programs. A number of family members/guardians commented on this.

- The staff in Harborview changed very little over the years. This is very comforting for parents and clients alike Harborview also did a terrific job of communication with us, helping with home visit arrangements, etc. They were like our extended family!
- There was greater permanence and professionalism at Harborview. I suspect there was also good cost accounting there too. Harborview provided more efficient use of state and federal facilities.
- Each person has different needs. Staff turnover frequency must be addressed. At HDC, a person's routine can continue if a staff person quits. Others (staff) know the routine. At Hope, ARCA, if the major caregiver leaves, the resident must endure discomfort and change.

## Economic Impact of HDC Closure

Information Insights has gathered financial information on 88% of the former Harborview Residents who were discharged in the last ten years. We have been unable to find any financial information on the remaining 12 percent of the former Residents.

The following table details the annual costs and average annual costs of services received by the former Harborview Residents who were discharged in the last 10 years and whose current costs could be identified:

**Current Status and Service Cost for Former Harborview Residents:1988-1997**  
**(1996 Harborview Cost of Care: \$164,000/person)**

Status	Number	Annual Cost All Residents	Annual Cost Per Resident
Deceased	18*	-	-
Grant-Funded Services	2	\$5,905	\$2,953
MRDD Waiver – Funded Services	62	\$4,398,307	\$70,940
Pioneer's Homes	5*	350,887	58,481
Unknown	12	?	?
Total	99	\$4,755,099	
Total Living and Known	69	\$4,755,099	\$68,914

\* 1 Pioneer's Home resident died during FY98; totals at end of year are 19 deceased / 4 Pioneer's. Pioneer's Home costs for the remaining 4 are expected to be \$299,864 per year, for an average of \$74,966. This would change the average cost for all known former Harborview residents receiving services to \$69,177.

In addition to the cost of services, however, other new costs are incurred by the State of Alaska for other benefits received by these former residents. Other benefits may include Food Stamps and Adult Public Assistance. Limitations in data access systems did not allow Information Insights to get an exact cost for these benefits, but based on other existing data sources we were able to develop a close approximation as follows:

### I. Adult Public Assistance

All but two of the HDC Residents discharged in the last 10 years were adults at the time of discharge. Each would have been eligible for between \$0 and \$45 per month in Adult Public Assistance prior to discharge. Post-discharge, each would be eligible for \$362 per month (or slightly less if receiving SSDI), for a net increase of \$317 per month (\$3,804 per year) in Adult Public Assistance, and a total cost for the 64 living and known former HDC residents who are not in Pioneer's Homes of \$243,456.

### II. Food Stamps

Most, if not all, of the former HDC residents are unmarried individuals, for whom receipt of Adult Public Assistance would make ineligible for more than the minimum \$10 in food stamps per month. The maximum

being received by the 64 living and known former HDC residents who are not living in Pioneer's Homes would therefore be \$640 per month, or \$7,680 per year.

A summary of annualized costs, by services received, shows the following:

**Cost of Services and Benefits for Former Harborview Residents: 1988-1997**

	Grant-Funded Services	MRDD Waiver Funded Services	Pioneer's Homes	Total Known Living	Unknown*
Number of Individuals	2	62	4	68	12
Annual cost of services	\$5,907	\$4,398,307	\$299,864	\$4,704,078	?
Additional cost of APA (maximum)	7,608	235,848	-	243,456	?
Additional cost of Food Stamps (maximum)	240	7,440	-	7,680	?
<b>Total annual cost of services and benefits</b>	<b>13,755</b>	<b>4,641,595</b>	<b>299,864</b>	<b>4,955,214</b>	<b>?</b>
<b>Average annual cost per individual</b>	<b>6,878</b>	<b>75,082</b>	<b>74,966</b>	<b>72,871</b>	<b>?</b>
<b>Total annual <u>state</u> cost of services and benefits</b>	<b>\$13,515</b>	<b>\$2,003,967</b>	<b>\$299,864</b>	<b>\$2,317,346</b>	<b>?</b>
<b>Average annual <u>state</u> cost of services and benefits</b>	<b>6,758</b>	<b>32,322</b>	<b>74,966</b>	<b>34,079</b>	<b>?</b>

\* Information Insights was not able to locate 12 of the 99 people discharged in the past 10 years from HDC.

In 1996, the Division of Mental Health and Developmental Disabilities contracted with Erickson and Associates to estimate the state cost savings from closure of Harborview Developmental Center and implementation of the Proposed Alternative Service Delivery. The Erickson study showed 1996 Harborview costs at \$164,000 per resident, and estimated Alternative costs at \$84,000 per resident, for a net savings of \$80,000 per resident. At the time, there were 23 remaining residents of Harborview. Two of the 23 have since died; following are the costs identified for the remaining 21:

**Comparison of Projected and Actual Cost for Services to Former Harborview Residents: 1997**

	Grant-Funded Services	MRDD Waiver – Funded Services	Pioneer's Homes	Total Known Living	Unknown
Number of Individuals	0	15	3	18	3
Annual cost of services	-	\$1,408,985	\$238,698	\$1,647,683	?
Additional cost of APA (maximum)	-	57,060	-	57,060	?
Additional cost of Food Stamps (maximum)	-	1,800	-	1,800	?
<b>Total annual cost of services and benefits</b>	<b>0</b>	<b>1,467,845</b>	<b>238,698</b>	<b>1,706,543</b>	<b>?</b>
<b>Average annual cost per individual</b>	<b>0</b>	<b>97,856</b>	<b>79,566</b>	<b>94,808</b>	<b>?</b>
<b>Total annual <u>state</u> cost of services and benefits</b>	<b>0</b>	<b>623,472</b>	<b>238,698</b>	<b>862,170</b>	<b>?</b>
<b>Average annual <u>state</u> cost of services and benefits</b>	<b>0</b>	<b>41,564</b>	<b>79,566</b>	<b>47,898</b>	<b>?</b>

Based on the data compiled for this study, the Erickson and Associates study was very close to the final projections. Excluding the individuals who are deceased or for whom we have no financial data, the average annual cost for the individuals discharged in 1996 and 1997 is \$94,800, of which \$3,270 represents benefits not considered in the Erickson study.

The Erickson and Associates study estimates, per individual, can be compared with actual costs as follows:

STUDY	Federal Funds	GF/MH Funds	Corporate Receipts	GF and GF Program Receipts	Total Costs
Erickson Study – Harborview	\$57,884	\$102,138		\$3,977	\$164,000
Erickson Study – Alternatives	31,111	43,526	3,362	6,057	84,257
Information Insights Study – Alternatives (excluding benefits not considered in the Erickson study)	46,810	44,728		3,340	94,878

The alternatives have thus saved both the federal and state governments, with the bulk of the savings going to the State of Alaska. In part, the difference in allocation of savings between Federal Funds and GF/MH funds is due to the change (since the Erickson report) in Federal Medicaid reimbursement from 50% of costs to 59.8% of costs.

**Community Impact**

The economic impact from Harborview closure is primarily on the community of Valdez, which loses the Harborview payroll and indirect impact of that payroll. At the same time, however, there is a relatively minor positive economic impact on the communities where the residents were discharged. Analysis of the distribution of community discharges shows the primary community impacts to be in Anchorage and Valdez.

<b>Community Discharge</b>	<b># of Individuals</b>
Anchorage	43
Bethel	3
Dillingham	1
Fairbanks	4
Ketchikan	3
Kodiak	2
Soldotna	2
Valdez	19
Wasilla	1
Unknown	2
[Deceased as of study date]	17

## **APPENDICES**

Former Resident Interviews  
Family Member/Guardian Survey  
Key Informant Interviews



## HARBORVIEW CLOSURE STUDY

### Former Resident Survey

Sample = 22 former HDC residents

1. How happy are you with your home or where you live?

	#	%
Very Happy	15	68.2%
OK	6	27.3%
I do not like it	1	4.5%

2. Do you feel lonely?

	#	%
No, Not often	13	59.1%
Sometimes	8	36.4%
Yes, often	1	4.5%

3. Does your family make you feel an important part of the family?

	#	%
Yes	10	45.5%
Sometimes	7	31.8%
No	5	22.7%

4. How safe do you feel in the neighborhood where you live?

	#	%
Very safe	18	81.8%
OK	4	18.2%
Not safe	0	

5. Do you get the services you need?

	#	%
Yes	14	63.6%
Sometimes	7	31.8%
No	1	4.5%

**What services or supports do you need that you don't have?**

- None (5)
- Dental (3)
- PT and recreation (3)
- Recreation
- Environmental modifications
- Better medical services
- More one on one time.
- Maybe more physical activity equipment
- More "on premise" things to do at home-physical activity
- "He's tired of his "job". A new goal could be to get him more involved into community. He needs more community integration, more group/community activities."

**6. When goals are set for you, do people:**

	#	%
Help you reach them	21	95.5%
Sometimes help you	1	4.5%
Don't help you reach them	0	

**7. Did you have a choice in your job or what you do most days?**

	#	%
Yes	7	35.0%
A little	7	35.0%
No	6	30.0%
No Response	2	----

**8. How much choice did you have in who you live with?**

	#	%
A lot	4	18.2%
A little	6	27.3%
None	12	54.5%

**9. Do you do fun things in your community?**

	#	%
Yes	16	72.7%
Sometimes	5	22.7%
No	1	4.5%

10. Do friends come over to visit your home?

	#	%
Often	2	9.1%
Sometimes	16	72.7%
Hardly Ever	4	18.2%

11. Do staff help you to be part of your community?

	#	%
Yes	15	68.2%
Sometimes	6	27.3%
No	1	4.5%

12. Do your neighbors treat you

	#	%
Very good	9	40.9%
OK	13	59.1%
Bad	0	

13. Do you have a job?

	#	%
Yes	5	22.7%
No	17	77.3%

14. Are you happy with the skills you learned on your job?

	#	%
Yes	3	60.0%
Not sure	1	20.0%
No	1	20.0%
Not Applicable	17	---

15. Are you learning skills that will help you get a different or better job?

	#	%
Yes	1	20.0%
Not sure	2	40.0%
No	2	40.0%
Not Applicable	17	---

16. Do you feel your job is worthwhile to you and others?

	#	%
Yes	3	60.0%
Sometimes	2	40.0%
No	0	
Not Applicable	17	---

17. When you want to go somewhere, do you have transportation?

	#	%
Most of the time	15	68.2%
Some of the time	7	31.8%
Almost never	0	

18. How well are the following kinds of services and supports meeting your needs in the community?

	0 Don't Know / No Response	1 Not well at all	2	3 Okay	4	5 Extremely well
Community Living Services	0		1	3	4	14
Mental Health Services	10	1		1	5	5
Recreation/Leisure	2			8	5	7
Nutrition	11			1	3	7
Transportation	8			5	3	6
Education	14		1	4	1	2
Employment	14	1	1	4	1	1
Behavioral Support	11		1	4	2	4
Health/Medical Care	0			5	6	11

	1 Not well at all	2	3 Okay	4	5 Extremely well	Well & Extremely well
Community Living Services		4.5%	13.6%	18.2%	63.6%	81.80%
Mental Health Services	8.3%		8.3%	41.7%	41.7%	83.40%
Recreation/Leisure			40.0%	25.0%	35.0%	60.00%
Nutrition			9.1%	27.2%	63.6%	90.80%
Transportation			35.7%	21.4%	42.9%	64.30%
Education		12.5%	50.0%	12.5%	25.0%	37.50%
Employment	12.5%	12.5%	50.0%	12.5%	12.5%	25.00%
Behavioral Support		9.1%	36.4%	18.2%	36.4%	54.60%
Health/Medical Care			22.7%	27.2%	50.0%	77.20%

19. Do you feel that your wants and needs were considered during the transition from Harborview to the community program?

	#	%
Yes	14	77.8%
No	4	22.2%
Don't Know	4	---

20. Do you feel that you were prepared and supported during your transition from Harborview to a community program?

- Yes
- Yes
- Yes, very supportive.
- Yes, some confusion and adjustment time needed
- Yes, as far as we know
- Very well
- "XXXX had a really hard time transitioning."
- "Yes. It took about 3 or 4 weeks for him to transition into new environment. Made more difficult because the staff from Harborview wasn't that familiar with him."
- "Somewhat. We made some trips to Anchorage and the Hope people came down here."
- "Everybody knew they were going to move here. There were no questions."
- "Not very well by Horizons."

21. Do you think your life has improved, stayed the same, or gotten worse since you left Harborview?

	#	%
Improved	17	77.3%
Stayed the same	4	18.2%
Gotten worse	1	4.5%

**Any additional comments?**

- Things more normalized, they don't have to wait for everything.
- They could use more community volunteers to take them out on activities-rather than "staff".
- He needs more opportunities to be out in the community
- Services are provided well for him. His guardians happy with levels of service.
- He is very happy in his new home. People have really seen the difference in XXXX.
- There aren't anymore behavior problems. He needs dental care
- It's really been good for him.
- Valdez needs to be more accepting. They won't even look at us when we are out to eat.
- The care she got at Harborview was really great.
- He is involved with a lot more people, more normalized living, and has more choices

### Additional Comments (cont.)

- It's good she's getting out into the community. The fears people have are unnecessary.
- He brings smiles to people in the community.
- I was hesitant initially about to move; my worries were unfounded. He's happier than he ever was.
- She is very happy. She is very lucky.
- XXXX has deteriorating health, the result of it not being monitored. We weren't informed of his medical condition. We were very happy with the care at Harborview.
- Positive change in seeing changes in personality. Decrease in seizure activity. Try to keep healthy diet for her. (Chews on toy)
- Great supports provided by ARCA.
- Having their own home has allowed them to develop in ways they couldn't have at Harborview
- Through the Anchorage Daily News "The Book Dreams" was able to get a "gate-trainer"

## HARBORVIEW CLOSURE STUDY

### Family/Guardian Survey

Sample = 18 family members/guardians of former HDC residents

1. Do you feel that you were prepared and supported during the transition of your family member from Harborview to a community program? Why?

	#	%
Yes	15	83.3%
No	3	16.7%

#### Why?

- The Division of Mental Health & Developmental Disabilities people were interested in cutting funds. Not in what XXXX needed. They wanted to cut her cost of care in half.
- They kept in good touch with us.
- We noticed XXXX didn't bring all his toys with him. Probably lost in HDC. Lynn George, of Assets, was the most supportive person we have ever dealt with. She was sensitive, paid attention to detail, and got things done.
- I was at Harborview for conferences over the years that the change was taking place, also I had letters and telephone conversations. They knew I wanted him to stay at Harborview as long as possible.
- I was prepared because of my experience in the field of D.D. I was supported by my friends.
- We made personal visits to Horizons and Harborview
- We were included in the planning
- The wonderful people at Harborview helped me, especially Ron Hursch.
- There were a number of meetings at ARCA to inform parents and legal guardians of the progress of the transition
- The social worker Ron Hursh informed me of the program and the move, etc.
- Harborview provided a safe, familiar home for XXXX since 1974. It was a shock to accept any change and it came on us suddenly. Probably no amount of time could have adequately prepared us.
- I was lied to by Mr. Hursch resulting in me making a trip to Alaska hoping to see XXXX in his new home arrangement. Instead I only got to see him under very bad conditions for about 6 hours.
- We had no say, was just told what would happen. We was very pleased with progress and chances to try new things
- Harborview kept in touch with us, letting us know when and how he would be transferred to Anchorage.
- I had telephone conferences with the Harborview staff and the Anchorage staff brought my husband and I into Anchorage during the planning stages.
- I was apprehensive that Harborview closing seemed to be moving rapidly in spite of public opinion. Control seemingly rested only in administrative hands

2. Do you feel that your views were considered during the transition of your family member from Harborview to the community program? Why?

	#	%
Yes	16	100.0%
No	0	
No Response	2	----

Why?

- Only because I knew my rights as a guardian, and I wouldn't give in. Several times during "negotiations" to get XXXX out of Harborview, state people threatened that we did it their way, or I could take XXXX home with me, and with no funding.
- The transition for me was scary at first because I did not know how things would work out.
- XXXX had a considerable period of "nothing" (no program) before he could enter CQL program-I didn't like this.
- I felt then and still feel that XXXX was better off there. There was more of a community feeling in Valdez and more people involved with his care, social life and fewer changes.
- Because I refused to be ignored
- There was some confusion to begin with. The problem was the care giver plan. However, Margaret Lowe came into the meetings and a most comprehensive care plan was implemented
- Because I think ARCA of Anchorage does really care for the patients
- Again the unknown is always scary, The social worker was very supportive and helpful. We felt our choices for XXXX were very limited
- They had a house picked out with high stairs and XXXX can't master stairs. In that house he would have been killed in less than a month
- Harborview gave us all the information on the different places we could check into, including Hope Cottage
- I wanted to see my brother more often and that was why I asked him to be moved to Anchorage. My opinions/wishes were considered.
- My mother, father (co-guardians) and myself advocated and made sure we were heard

3. Do you think that community programs or institutions like Harborview provide greater permanence for people with developmental disabilities?

	#	%
Community programs	5	45.5%
Institutions	6	54.5%
No Response	7	---

Why?

- I used to think they did until Harborview closed
- Institutions are more permanent. So are coffins. The permanence and lack of looking at new and better ways of doing things are a definite negative. "Normal" people don't have permanence, and that's often to their advantage.
- Yes, it's nice to work together but it also is nice to have privacy.
- Each person has different needs. Staff turnover frequency must be addressed. At HDC, a person's routine can continue if a staff person quits. Others (staff) know the routine. At Hope, ARCA, if the major caregiver leaves, the resident must endure discomfort and change.



**Question 3 (cont)**

- As long as they are like Harborview. It never did have an "institutional" feeling-more like a combination of resort and large home. The small town is another reason that it was so successful. The community was so involved with Harborview, and Harborview with the community.
- Permanence is not the primary issue. A coffin in the ground is more permanent than a community program. A jail cell in a federal penitentiary is more permanent. Life is not permanent-I wasn't after permanence for XXXX.
- There was greater permanence and professionalism at Harborview. I suspect there was also good cost accounting there too. Harborview provided more efficient use of state and federal facilities.
- It is a more "home-life" environment and more community oriented for the client.
- I never did consider Harborview an institution, because of the excellent treatment by staff and a wonderful doctor there. Also the whole community took pride in the people staying at Harborview.
- Previous to the present transition XXXX had spent ten months in a group home under Hope Cottages. That was a disaster. So I fought closure of Harborview. However, the care that he now receives at Collie Hill Way does not in anyway resemble Hope Cottages.
- The staff in Harborview changed very little over the years. This is very comforting for parents and clients alike Harborview also did a terrific job of communication with us, helping with home visit arrangements-etc. They were like our extended family!
- Yes, because people like my brother XXXX need constant care and professional people to teach them all that they are capable of learning
- They have more freedom to travel and do things that can't always be done when they are part of an institution. They are a part of the real world.
- So far I'm pleased with XXXX's community program, but I believe this answer could vary according to an individual's circumstances and the verdict could still be out. Financial permanence is hopefully not at risk as well.

**4. Do you think your family member's life has improved, stayed the same, or gotten worse since he/she left Harborview?**

	#	%
Improved	10	71.4%
Stayed the same	3	21.4%
Gotten worse	1	7.1%
No Response	4	----

**Why?**

- Drastically improved. She lives in her own home. Her care provider is tuned in to XXXX
- More individual attention
- We are unable to monitor foster home for abuse potential. We could always drop in at HDC any time. Not able to discover how much "nothing" time XXXX has at his home. We believe mental stimulation is important. However, his teeth are cleaned well.
- I think it is because of the changes of personnel. He was used to move consistency.
- Institutions are like a parallel universe. Life and institutions like HDC are apples and marbles. HDC was an eddy in the river of life-a stagnant eddy, a holding pattern in the flight of life.
- XXXX seems happier, smiles more at Eagle House.
- The environment of a home rather than an institution has improved the quality of her life.
- She is getting good care now, but XXXX and everyone was especially treated like family at Harborview.

#### Question 4 (cont.)

- Because his needs are taken care of and he is also taken to movies and dinner or lunch every so often and he sees a doctor at Alaska Native Medical Center, he is happier.
- XXXX's care provides have changed numerous times since moving to ARCA. I believe 5 to date. Of these 5, 2 related well and XXXX and she was obviously well cared for healthy and happy!
- I don't know. I can only take the word of his caretaker.
- I'm putting improved because he's doing so well, but I really don't know that much about Harborview because we never went there to visit.
- More 1 on 1 attention by his care givers. More opportunities to go out on drives and out in the community
- XXXX likes his privacy and is much more relaxed in his new home situation.

#### 5. What kinds of changes have you observed in your family member since he/she left Harborview?

- A huge reductions in bizarre and violent behavior. At Harborview, she was the "baddest of the bad". Now she is quiet, seems happy, and has no violent behaviors. Her health has also improved.
- More independence
- With different medication, he seems less likely to bite his lip. He has opened lip for many years
- He has not taken the personnel changes well. He became destructive and depressed when two of the girls who had been daytime workers and had been with him for over a year and both left in September 1997.
- There is closer family bonding
- None, since I haven't seen her, but I know she is happier, healthier, and doing lots of things. That's enough for me. She now has a life. She didn't at HDC.
- XXXX seems happier.
- I don't know
- Since I can now visit XXXX several times a week he has gotten to know me. He will now let me help feed him. At Harborview he'd turn his head away.
- Improvement in his behavior except for finger twisting once in a while. His health is better. mentally and physically.
- No real changes except when one of the care providers that she really related to left. She was very depressed. Her home visit at that time was a disaster. Another time when providers changed she gained too much extra weight due to lack of exercise and change in routine.
- Haven't had much opportunity to visit often enough to note.
- He really likes his home and the caregivers that stay with him. When I visited him he was happy and seemed content.
- I never visited XXXX in Harborview, so I don't know
- I rarely saw him when he was in Harborview, so I am still getting to know him, but I hear that he knows more vocabulary now and he is pretty much happy in his new life. A visit to McGrath is planned for him to see his family out here. That is a milestone.
- Much calmer and consistent, plus he even goes to work and events. Being part of the community does seem to benefit him. His independence has improved.

The following are questions about the community services and supports your family member has received since leaving Harborview Developmental Center. If you are not sure about your family member's experiences in a particular question, please check 'don't know'.

**6. How happy are you with the where your family member is living?**

	#	%
Very happy	11	64.7%
OK	6	35.3%
I do not like it	0	
Don't know	1	---

**7. Do you think that your family member feels lonely?**

	#	%
No, Not often	9	69.2%
Sometimes	4	30.8%
Yes, often	0	
Don't know/ No Response	5	---

**8. Do you think your family member feels like an important part of the family?**

	#	%
Yes	7	58.3%
Sometimes	5	41.7%
No	0	
Don't know	6	---

**9. How safe do you think your family member is in the neighborhood where he/she lives?**

	#	%
Very safe	10	58.8%
OK	7	41.2%
Not safe	0	
Don't know	1	---

**10. Do you think your family member gets the services they need?**

	#	%
Yes	14	82.3%
Sometimes	3	17.7%
No	0	
Don't know	1	---

**What services or supports do you think they need that they don't have?**

- I think all of her needs are well met.
- Unable to get a support person through Assets to take XXXX in community and give 1 to 1 in home with his toys.
- Getting out more. travel
- Used to enjoy swimming, not available now
- I'm in hopes that this summer they will be able to take the children for more outings and picnics
- I believe Laura received more instructional on or one at Harborview, through Herman Hutchins school
- They are working on suggested ideas

**11. When goals are set for your family member, do people:**

	#	%
Help him/her reach them	12	80.0%
Sometimes help	3	20.0%
Don't help	0	
Don't know/ No Response	3	---

**Do you think that the program has reasonable goals for your family member?**

- Yes (10)
- I set the goals with her care provider-very XXXX-oriented goals
- Yes, but perhaps set unrealistically
- Yes, we were included in making the goals

**12. Did your family member have a choice in job or what he/she does most days?**

	#	%
Yes	5	38.5%
A little	4	30.8%
No	4	30.8%
Don't know/ No Response	5	---

**13. How much choice did your family member have in choosing with whom he/she lives?**

	#	%
A lot	4	28.6%
A little	3	21.4%
None	7	50.0%
Don't know/ No Response	4	---

14. Does your family member do fun things in the community?

	#	%
Yes	11	64.7%
Sometimes	6	35.3%
No	0	
Don't know	1	---

15. Does your family member have friends that come over to visit?

	#	%
Often	2	15.4%
Sometimes	8	61.5%
Hardly Ever	3	23.1%
Don't Know/ No Response	5	---

16. Do staff help your family member take part in the community?

	#	%
Yes	12	66.7%
Sometimes	5	27.8%
No	1	5.6%

17. How do your family member's neighbors treat him/her?

	#	%
Very good	3	42.9%
OK	4	57.1%
Bad	0	
Don't know/ No Response	11	---

18. Does your family member have a job?

	#	%
Yes	4	25.0%
No	12	75.0%
Don't know	2	---

19. Are you happy with the skills your family member has learned on his/her job?

	#	%
Yes	6	54.5%
Not sure	1	9.1%
No	4	36.4%
Don't know	7	---

20. Is your family member learning skills that will help him/her get a different or better job?

	#	%
Yes	0	
Not sure	4	44.4%
No	5	55.6%
Don't know/ No Response	9	---

21. Do you feel your family member's job is worthwhile to him/her and others?

	#	%
Yes	3	50.0%
Sometimes	2	33.3%
No	1	16.7%
Don't know/ No Response	12	---

22. When your family member wants to go somewhere, does he/she have transportation?

	#	%
Most of the time	14	93.3%
Some of the time	1	6.7%
Almost never	0	
Don't know/ No Response	3	---

23. How well are the following services and supports meeting the needs of your family member in the community?

	0 Don't Know / No Response	1 Not well at all	2	3 Adequate	4	5 Extremely well
Community Living Services	5			3	4	6
Mental Health Services	9			4	1	4
Recreation/Leisure	4		1	2	4	7
Nutrition	15			3	5	5
Transportation	4		1	3	5	5
Education	10	1		4	2	1
Employment	13			2	1	2
Behavioral Support	8			1	5	4
Health/Medical Care	5			2	5	6

	1 Not well at all	2	3 Adequate	4	5 Extremely well
Community Living Services			23.1%	30.8%	46.1%
Mental Health Services			44.4%	11.1%	44.4%
Recreation/Leisure		7.1%	14.3%	28.6%	50.0%
Nutrition			23.1%	38.5%	38.5%
Transportation		7.1%	21.4%	35.7%	35.7%
Education	12.5%		50.0%	25.0%	12.5%
Employment			40.0%	20.0%	40.0%
Behavioral Support			10.0%	50.0%	40.0%
Health/Medical Care			15.4%	38.5%	46.1%

Any additional comments?

- Although XXXX has been out of Harborview for 7 years, she still reacts if you take her onto the grounds. She will grab your hand and pull you away from Harborview. She can't verbalize her feelings, but her actions clearly tell us that she never wants to be in that place again!
- Since being here in Anchorage: 1) Now uses wheel chair in community, since refuses to walk frequently. 2) Sees parents 1-3 hours a week, when parents (snowbirds) in town. 3) More knowledgeable medical, dental assistance. 4) Foster family does BEST job of dressing him well, cleaning his teeth. 5) Easier for parents, rather than a 7 hour trip to Valdez.
- Gail Franklin is receiving excellent care, considering she totally dependent on others for all her needs.
- It's sure been a long time coming. Thank heavens HDC is closed!
- Horizons Unlimited seems to be improving (under the goal of a local whistle blower, Sultana Sanders). The Horizons Unlimited management probably did not have the training, expertise to replace upper, lower level management at Harborview.
- XXXX is well-cared for. We are pleased that the quality of her life has improved.

### Additional Comments (cont.)

- Like I said, Harborview was the best place I had seen for people with a mental handicap. I credit it (the care, etc.) to the city of Valdez's residents and the whole staff at Harborview. I was so sad to see such a wonderful place like Harborview to shut down.
- The staff at Collie Hill Way is very cooperative. The parents and legal guardians have a meeting once a month to iron out any problems. I'm very pleased with XXXX's care in his new home.
- Our real concern for XXXX is the change of XXXX's care provider in her home. It is good to have her in Anchorage and easier to see her on a drop in basis and easier to bring her home for visits. The directors and management staff at ARCA are very professional and in tune to our concerns.



## HARBORVIEW CLOSURE STUDY

### Key Informant Interview

#### Interviews:

Bob Gregovich, Former DMHDD Administrator, Juneau  
Duane French, Director of DVR, former director of ACCESS Alaska  
Diana Ray, DMHDD, Juneau  
Dave Stewart, DOA Division of Personnel, Juneau  
Eva Dunning, Director, Connecting Ties, Valdez  
Gregg Erickson, Erickson and Associates, Juneau  
Gloria Hawkins, Bethel Community Services, Bethel  
Janice Johnson, Prince William Sound Community College, Valdez  
Jeff Jessie, Director, AMHTA, Anchorage  
James Kohn, Director, Division of Alaska Longevity Programs, Anchorage  
Jackie Orтели, Administrator, Denali Center, Fairbanks  
Margaret Lowe, Associate Director, ARCA, Executive Director of ARCA Foundation, Anchorage  
Steve Lesko, Director, Hope Cottages, Anchorage  
Vernell Sodergren, Director, Horizon's Unlimited, Valdez  
Winnie Crosby, Director, FCS, Soldotna  
Yvonne Chase, Director, Division of Community & Rural Development, DCRA, Anchorage

#### 1. What role did you play at Harborview or in the closure of Harborview?

- Taught college courses as part of HDC staff training, part of organizing group that served people moving out of HDC to Horizons Unlimited, which has been in existence for 13 years. Played advocate role in providing less restrictive environment for people at HDC.
- Program administrator 1973-1987. Responsible for reducing the number of clients living at HDC to 50. Not involved in the final push of the closing.
- Chair of the Governor's Council's Residential Services Task Force to develop plan to close HDC. Held public forums in Valdez for people to express concerns, etc.
- Member of labor management committee, wrote the 3 year plan that was implemented. Chaired Commissioner's HDC closure team, worked with cost analysis.
- Chaired the statewide labor management committee that was in charge of issues of HDC staff during the closure of HDC.
- Held several positions at HDC over the years. Was the vocational coordinator the last few years. Started a 2<sup>nd</sup> hand store in Valdez to help people from HDC get out into community and work. Has been separated from HDC since 1994.
- Contractor that did HDC closure study required by state contracts with labor union.
- Program took three consumers from HDC in 1994-95.
- Former Senior Attorney at Disability Law Center. Advocated for right of people to live in least restrictive environments, assisted in developing financial package of phase out and closure of HDC
- Pioneer Home Administrator, admitted 8 from Sourdough Unit. One person died shortly after admission and one moved to Denali Center.

- Director of DMHDD from 1991 to 1993. Commissioner of Health and Social Services from 1994-95. Advocated for the closure of HDC in both positions
- Strong advocate for “no admission” policy for HDC. Intimately involved with HDC for the past 20 years. Program was accused of trying to destroy HDC at one point.
- Was an HDC employee. Involved with a Valdez alternative agency now.
- Agency took last 2 residents out of Sourdough Unit. Advocated for closing HDC through ADD, Key Campaign, & Governor’s Council.
- Commissioner’s designee to oversee closure and participated on labor management committee from 1995-96. Supervised DMHDD and overall Administration.

**2. Were there adequate supports for consumers, families and guardians during the transition process?**

	#	%
Adequate	12	85.7%
Somewhat	2	14.3%
N/A or No Response	3	

- Yes (4)
- I believe so. People maybe didn’t have all that they could have. Really was a leap of faith that services would be there and be better.
- Parents/guardians were concerned children wouldn’t have as many staff in community placements for supervision as there had been in the institution.
- Yes. There were systematic ways for family/guardians to make transition. There were some problems and concerns during the process.
- For consumers at HDC—but Alaska has a long way to go in providing community services.
- A cynical yes, but supports set expectations that services would continue at the same level permanently. Families thought they would be getting everything needed but this was not always the reality.
- Support was very positive from our view—families were able to choose home. Very happy to get all the help they got.
- Absolutely, especially during the last phase, the supports needed varied. The State did an extraordinary job of supporting people with all of their needs.
- Yes, very adequate supports. DMHDD was very supportive in reviewing needs and wants and assisting with funding.
- Our consumers had public guardians and got lots of support from DMHDD and HDC staff. They gave us information and tips. Our staff was able to spend time at HDC prior to the transition. They gave us behavior management ideas for clients as well.
- I think there were but I wasn’t there as the final clients left. The beginning is where there were the most snags. Division did well to keep needs of clients and families at the top of list and making sure the supports were there.

3. Do you think that community placements were based on the individual's needs and wants or on what was available?

	#	%
Needs and Wants	9	52.9%
Availability	0	
Both	8	47.1%

- Needs and wants (4)
- Both. Always have to consider what's available and feasible. Mostly based on needs and wants of clients.
- It was a mixture of wants and realities. The service systems haven't changed enough to design services around people. They still have to adjust to fit services.
- Placements were based on the wants of the family because our clients are not able to speak. Families are very happy.
- Placements were based on what was available. Families and guardians were asked for what they wanted. Only when it worked were the wants listened to. State still in a mode of fitting people into programs instead of programs to fit people.
- They had a choice of 6 locations. They could choose the region where they wanted to live, which is better than only one choice - Valdez.
- Both. I know of one case where a person was unable to return to their home village but they were able to receive services in a nearby village.
- People got to choose the environment, with whom, and where to live. When possible, they were involved with construction and furniture planning. I don't know of anyone arbitrarily forced into a placement. They had a broad range of choices. Permanence and stability are very important—we put leases in clients' names instead of the program's—in order to nurture a feeling of permanence.
- In most cases people's wants and needs were considered and met. Choices were limited to what was available. Wants and needs are becoming more identifiable and clear for people the longer they live outside of HDC.
- Every effort was made to place people where they wanted to live, but sometimes a village preference wasn't an option. Overall, consumer's wants were the most important consideration of placement.
- Based on needs and wants, the Department went out to bid where facilities didn't exist. Sometimes homes needed to be built in order to meet the needs of families.

4. Do you think that communities and community service providers were given adequate support in preparing to provide services to former HDC residents during the transition process?

	#	%
Adequate	12	80.0%
Somewhat	3	20.0%
Not Adequate	0	
N/A or No Response	2	---

- Yes (4)
- Because it was done over 7 years, people were given plenty of time to plan support services for those coming out of HDC. Providers may not have had much experience providing services to people coming out of

institutionalized lifestyle. There is always room for improvements by the state. The closure was seen as an opportunity to provide services more cheaply. Dropping costs lowers the quality of services. Now community providers are asked to do more for less.

- People in community services already had training, but we needed more training. The opportunity was there but I didn't ask for help because I was unsure of what we needed help with, which wasn't the State's fault.
- Yes, the transition was good. DD programs had lots of support, especially from HDC staff
- There was adequate support. The Division could have listened to agencies and consumers better but they had a mission to carry out and that's what they did.
- The Pioneer Homes hired some of the HDC staff who went directly to Pioneer Homes with those moving from the Sourdough Unit. The state posted the jobs at HDC and paid for the cost of transportation for job interviews. There were 7 positions transferred from HDC to the Pioneer Homes with another 56 people hired in various positions. DMHDD was very supportive and provided funding for the 24 hour services needed for some of the former HDC residents. HDC staff also came to Anchorage to help train Pioneer Home staff in caring for specific consumers.
- We received tremendous support—more than we expected.
- Clearly a great deal of pre-admission preparation took place. There was lots of support from HDC staff and families and guardians.
- Absolutely. I don't think they could have done better. We had the time, budget and support we needed from the state, communities and HDC staff. It was extraordinary.
- Yes, locally it was easier for us to develop the transition process. We were more fortunate than "out of town" agencies. We knew them and could train staff during the transition easier than agencies outside of Valdez.
- Our program was given adequate supports during the transition. We received supports from DMHDD, guardians, and HDC staff. They all went out of their way to be supportive in helping.
- Yes, for the most part. It depends on how you define support. There was lots of attention to agency support. Some of the community agencies involved underestimated the needs of some of clients.

**5. Do you think that former resident's have access to the services and supports they need in community placements? If no, what services and supports do they have less access to?**

	#	%
Yes	8	57.1%
Yes, with concerns	6	42.9%
No		
N/A or No Response	3	---

- They have access to the services needed.
- Yes, however, they do need to improve the availability of activities and work. People need something meaningful to do
- The more we integrate into community, the more we integrate into the problems of the community. HDC provided a completely artificial environment. Communities are prejudiced against people with disabilities. People were isolated against this in HDC. We need to find ways to avoid the isolation with services like transportation. When in community, they begin to see "real life" relationships, etc. which were never explored while in artificial environment

- People are more aware of what their needs and wants now. So in future, more services will probably need to be provided.
- People now have access to whatever is needed. There was a full comprehensive plan done for each resident.
- The basic supports are there. Agencies are working hard to provide related services like physical and occupational therapy, which are difficult to access across the state.
- In our homes, people have access to all services. There is nothing that they received at HDC that they are not receiving now in the Pioneer Homes.
- In Valdez, yes. Because of the smallness of the community, there is easy access to services. Even the fire department is involved in addressing safety issues. The doctors are great. There are some transportation problems, but nothing much.
- Medicaid regulations are creating major hassles for accessing specialized medical services for some clients in Kenai.
- It depends on community. Sometimes the entire range of services is available as it was at HDC. Smaller communities have fewer available resources.

**6. In your opinion, how well are the following service needs being met for former HDC residents in community programs?**

	0 Don't Know / No Response	1 Not well at all	2	3 Okay	4	5 Extremely well
Community Living Services	4		1	5	3	4
Mental Health Services	4	2	4	3	3	1
Recreation/Leisure	3		3	2	4	5
Nutrition	2			1	8	6
Transportation	5		3	3	3	3
Education	6	1	1	7		2
Employment	3	5	2	4	2	1
Behavioral Support	4			6	6	1
Health/Medical Care	4			3	3	7

	1 Not well at all	2	3 Okay	4	5 Extremely well
Community Living Services		7.7%	38.5%	23.1%	30.8%
Mental Health Services	15.4%	30.8%	23.1%	23.1%	7.7%
Recreation/Leisure		21.4%	14.3%	28.6%	35.7%
Nutrition			6.7%	53.3%	40.0%
Transportation		25.0%	25.0%	25.0%	25.0%
Education	9.1%	9.1%	63.6%		18.2%
Employment	35.7%	14.3%	28.6%	14.3%	7.1%
Behavioral Support			46.2%	46.2%	7.7%
Health/Medical Care			23.1%	23.1%	53.8%

7. Many parents and guardians fear that community programs are more likely to lose their funding than institutions like Harborview. Do you think that community programs provide the permanence which families and guardians rely on and expect? Why?

	#	%
Yes	7	43.8%
Somewhat	7	43.8%
No	2	12.5%
N/A or No Response	1	---

- Yes, these programs do and probably will continue to be funded by the state. Parents are always going to have some apprehension.
- The illusion of permanency of HDC is shattered. There isn't the stability and assurance that services will be as readily available. Nonprofits don't compensate people as well as state jobs.
- I think they do. Human issues aside—people will look at community programs. People are discharged from institutions, not communities.
- Yes, I think people want to make sure their family members are taken care of. I think the majority is happy with the services they are getting now.
- Yes, the state was very supportive of programs that we've started. The support seems to be continuing and is stable right now.
- Permanence depends on the legislature and funding. Community programs will continue unless the state decides to cut funding. We have to continue to be vigilant in advocating. We can't trust that the state will continue to see people with disabilities as a priority. Stronger funding is still not a good reason for people to stay in institutions. People with disabilities are still not as politically influential as other groups.
- There is no guarantee achievable in a political system.
- The Pioneer Homes are "community facilities". We spend \$30 million a year for 600 seniors for community programs.
- Not really. We should promote programs that improve quality of life.
- Yes. Because the state will not go back on their word that they will take care of these people. It doesn't matter if its HDC or community programs.
- I hope that community services will be able to provide the permanency that people need and want. The state is responsible and hopefully, will always be responsible for providing community support for people
- I hope they do. I think legislators have the knowledge of and respect for the community programs but you never know for sure. The whole DD system with the waiting list causes insecurity. DD services are not an entitlement. Some families were on the waiting list for 5 years and are still afraid of having services dropped at any time. Many families may not be comfortable, especially older parents.
- Permanence didn't occur at HDC. Community agencies have a long track record with reasonably stable funding sources. They are more diversified and have balance of funding.

**8. In your opinion, has the closure of HDC and movement of people into community resources been cost effective? Why?**

	#	%
Yes	11	68.8%
Not Clear Yet	3	18.8%
Uncertain	2	12.5%
N/A or No Response	1	---

- Certainly. Services in the community are much more cost effective both monetarily and in human terms.
- Most definitely, but at the expense of people with disabilities and providers. More for less is expected.
- Absolutely. Medical and behavioral needs decrease.
- Yes, it's cheaper to live in community—caretaker wages are much lower. (I lost \$10,000 with my job change).
- They also may not get as much preventative medical and dental care.
- Yes. The same if not more of services are available in the community—plus being close to the family.
- Yes, people can be supported in community at lower cost. The major difference in cost is that providers are paid far less than at HDC. This impacts continuity and recruitment, and employee benefits can't match state's benefits plan. This is not a reason to go back to institutionalizing people but it's important to support community service providers with quality pay and benefits.
- Yes, extremely. Look at the costs of supporting a Sourdough resident at HDC - \$160,000. Higher costs were due to the distance and expense cost of living in Valdez, pay differentials, and the size of the Sourdough Unit.
- Absolutely. More so as years go by. The service plans of some of the former residents were "front loaded". We may see more saving in 3 years.
- Yes, the people I work with are much happier and their life style is less restricted. They choose their own food and activities. I do think HDC was one of the best but institutions are not able to individualize people's needs.
- Cost is 1/3 less per consumer and probably will continue to decline as initial transition costs decline.
- I don't know. There were some initial savings, but whether these are sustainable will have to be determined. Also, how can we put a price tag on quality of life?

**9. Do you think the closure of Harborview has had a positive or negative impact on the lives of the former residents if the facility? Why?**

	#	%
Positive	12	75.0%
Negative	0	
Both	2	12.5%
Uncertain	2	12.5%
N/A or No Response	1	---

- Positive, due to reports given of happiness from residents I am in touch with. They have expressed great satisfaction.
- Positive. Institutions like HDC are completely protected/artificial. They rob people of the richness of community and being integrated into a community. They need to be closer to the "American Dream." They are more likely to get caught up in it and make it true for themselves if they can see it. Living in the community

means opportunities to work, families, volunteer in community, recreational opportunities. to be neighbors and friends with people who are not PAID to be there!

- Positive. A whole world opened to them now that hadn't seen before—they have more choices and freedom.
- Positive. One girl I worked with at HDC—I do respite now—I had never noticed that she has a sense of humor before.
- Positive. They used to say that they would only eat certain foods—but here, they get involved with choosing what they eat. They are more interested and take an active part in the preparation of food and have increased appetites.
- For the most part positive. They now have a "homelike" environment that is less regimented. They have more opportunities to make choices. I can't say it's best for everyone because I don't have that knowledge.
- Both. Disruption causes high stress for some more than others. Not everyone is better off.
- HDC didn't feel "homey" at all—not anything like the Pioneer Home environment. It is much less restrictive here, people can do more for themselves—they are able to get their own food and snacks in their own kitchen.
- The care at HDC was based on a medical model and the Pioneer Homes are based on social model approach—supporting people in what they can do in a "home like" environment. There was a very positive impact on people with dementia who tend to do better in a homelike environment.
- It's hard to judge. The feedback is generally positive.
- Positive. Living in the community and in community based services provides a much better quality of life.
- Absolutely. You have to be there to see it. Joy, family reunification in some instances, better health, more involved in the community (having block parties - you don't get that in an institution)
- Positive. We see people all the time initiating activities. More opportunity to choices
- Positive impact. They're making their own decisions, which you would never think possible from reviewing past records.
- Like any decision that affect so many, there will be positive and negative effects. The changes I've seen are very positive. There is a small percentage who may do better in different setting, but its not fair to say all are doing perfectly well.

**10. Do you have any examples of how a former resident's life has improved since discharge? Any examples of how a former resident's life has been negatively impacted since discharge?**

- A Valdez group home manager reported how much people's lives have changed, from sitting in a corner eating cookies at HDC to having their own kitchen. Now when they need a snack, they can not only choose what it will be, but go and get it independently. Now, they have something to look forward to.
- I've seen them out in the community at restaurants, movies, etc. Folks are taking part in their communities now.
- People are getting to go out to the mall or moving back to rural settings.
- One person was able to visit family members in California for the first time. A Kenai consumer had refused to move a trunk of his clothes into his room at HDC, but when he moved into a new community based home, he said, "now I can move my stuff in—because I have a room."
- Mental health consumers are more lively—socialization is more open and people are actively participating in culturally appropriate activities—like sewing fur, fishing (fish camp in summer and ice fishing in winter).



- One of the former residents living in Kenai is so proud and happy to have a bedroom door that can be closed for privacy and so he can play his music as loud as he wants. He couldn't do that at HDC.
- Some people had violent behaviors at first but now their behavior is managed without large amounts of medication.
- Former residents are having a dramatic increase in family contact, from none to daily, in some cases.
- I've had the opportunity to follow the lives of 5 people. In every case, their health is better, they are doing more, are more active and more productive in terms of functioning level. In 3 of those 5, the families are very happy with the quality of life of their family member.
- In some of the people, there was never a spark in their eyes while at HDC—now they laugh and smile!
- The majority of the people we support were at HDC at some time. Now, if someone is hungry or thirsty they can go into the kitchen and get some food and water. At HDC, they had to wait for these things to be offered first. There have been great improvements, especially with the lower functioning folks.
- Two former residents were amazed they could shut the door to their bedrooms. They enjoy having privacy and a choice of churches to attend, and are doing more personal care willingly because they want to look good.

#### **Any additional comments?**

- I'm glad HDC has finally closed. It should have closed 10 years ago though. The state has finally learned that institutionalizing large groups of people under one roof is just not effective.
- As long as we have to work within governmental systems, then we are prone to become systematic in our thinking. This compels us to do studies and surveys when we should already know in our heart that we've done the right thing by closing HDC and bringing people closer to those who naturally love and support them.
- Closing HDC was the best thing the state could have done from financial and human perspectives.
- At HDC, behaviors (acting out) started to improve in the end when staff and patient ratios started to change. Staff from HDC came with the former residents and stayed for few days during the transition. These were the most difficult clients to be placed. We were nervous in the beginning not knowing how dangerous or severe the former resident's behavior would be.
- I think there's a place for HDC—something. Overall the community is better for them—its good to see them in community.
- I strongly supported the closure but was cynical about it also. There was micromanaging of agencies that could have been avoided. The state has a long way to go in perfecting the system but we are moving in the right direction. We need to find balance between giving agencies the support needed and micromanaging. Agencies need to be able to make decisions independently based on local needs. The Division made arbitrary and politically expedient decisions at times.
- Residents transferred from the Sourdough Unit to Pioneer Homes were not good candidates for "community placements". They were unique because they had progressive dementia that made their care difficult. They were difficult to place anywhere.
- Why did it take so long to close HDC? Medicaid Waivers helped the process of closure.



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