

## ISSUE ANALYSIS AND OPTIONS BRIEF

### ALASKAN'S AT-RISK OF OUT-OF-STATE PLACEMENT DUE TO COMPLEX BEHAVIOR MANAGEMENT NEEDS



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### Issue Analysis and Options Brief

The Western Interstate Commission for Higher Education (WICHE), in partnership with the State of Alaska - Department of Health and Social Services (DHSS) and the Alaska Mental Health Trust Authority (The Trust), prepared this Issues Analysis and Options Brief - Alaskan's At-Risk of Out-of-State Placements due to Complex Behavior Management Needs.

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**EXECUTIVE SUMMARY**

In partnership with the State of Alaska - Department of Health and Social Services (DHSS) and the Alaska Mental Health Trust Authority (The Trust), the Western Interstate Commission for Higher Education (WICHE) prepared this issue analysis and options brief to assist DHSS in developing and understanding the options available to meet the needs of persons who are now being placed out-of-state or are at risk for out-of-state placement due to complex behavior management needs and who pose an extreme risk of serious self injury or assaultive behavior resulting in injury to others.

**The individuals targeted** for this Project were Trust beneficiaries (persons with a developmental disability, mental illness, Alzheimer's and other dementias, or other cognitive impairments or chronic alcoholics with psychosis) who experience one or a combination of disorders and are difficult to place and serve within the State of Alaska, due to their complex behavior management needs.

**The challenge** noted at the onset of this Project, the lack of an Intermediate Care Facility for the Mentally Retarded (ICF-MR) and other intensive resources to address the needs of the targeted population in Alaska was clearly recognized by all engaged stakeholders. Alaska does not currently have a safety net to safely provide treatment services for some individuals, regardless of age, with disabilities and complex behaviors.

The creation of a full continuum of care is needed for individuals with a developmental disability, mental illness, Alzheimer's and other dementias, or other cognitive impairments or chronic alcoholics with psychosis, who experience one or a combination of these disorders. Additionally, subsets of this population - persons who are difficult to place and serve within the State of Alaska because of complex behaviors - need dedicated, specialized resources and services. Individuals with complex medical needs also require specialized resources that are not readily available within Alaska, although this population is not the focus of this report.

In order to develop this Issue Analysis and Options Brief, the WICHE Mental Health Program staff:

- Examined relevant literature, available data and reports from Alaska and other states;
- Conducted key informant interviews;
- Captured client-level data about individuals who represent the target population; and
- Examined and reported upon Medicaid options used effectively by other states to fund services for the target population.

A critical decision point is whether the Department of Health and Social Services is willing and able to invest in the development of resources within the State to eliminate, or at least minimize the need for out-of-state placements, or if the preference is to expand the availability of out-of-state placements.

Either option has associated costs. Developing a more robust continuum of care for individuals with disabilities and complex behaviors cannot occur immediately, but can begin incrementally as an investment in the treatment of Alaskans in the future. The highlights of policy options that follow are based on the premise that Alaska will elect to enhance existing programs and services and develop additional programs, services, and supports to provide a more robust continuum of care and effectively treat individuals with complex behaviors within the State.

These policy options are grouped by, 1) Children and Adults, 2) Older Adults, and 3) All Individuals. Implementing the most suitable options will require sustained leadership and an investment in resources and staff time over many years. However, the planning with incremental steps can begin at any time and the sooner an investment in individuals with complex behavioral management needs begins, the sooner the individuals can return or remain closer to their home communities.

### Children and Adults

- Implement a demonstration project, through an RFP process, consisting of three to four small ICF-MRs or other intensive, structured alternatives specializing in the treatment of individuals with complex behavioral challenges.
- Implement a demonstration project in which 10-20 individuals with co-occurring disabilities who also exhibit serious complex behaviors are identified. Develop a specific funding and resource pool for these individuals either with new dedicated funding or with contributions from existing systems already serving these individuals.
- Consider a lease arrangement or partnership with Westcare Management, Inc. to provide acute crisis assessment and stabilization services along with intensive behavior management treatment within Alaska.
- Explore reducing the minimum age for admission to group homes to less than 18 years. Many of the individuals identified at-risk of out-of-state placement are transition-age youth 14 - 25 years old.
- Consider requiring national accreditation, such as through the Commission on Accreditation of Residential Facilities (CARF) or Joint Commission for community-based programs to promote quality standards and quality treatment standards across the State.
- Implement a utilization review process for out-of-state placements for adults, similar to the one in place for children.
- Review the service assessment and approval processes to identify opportunities for increased efficiency and quality. Determine if the ICAP Assessment Tool used by the developmental disability system meets current assessment needs.

### Older Adults

- Seek a clarification/interpretation from the State's Attorney General's Office about the ability of Pioneer Homes to admit older adults with serious mental illnesses. Then determine if admitting these individuals is supported by the State/DHHS and whether any regulatory changes would be needed to permit this.

- Explore the costs and benefits of reducing the admission age at Pioneer Homes to 55 or 60, instead of the current 65, with special considerations for individuals with serious mental illnesses, Alzheimer's and other dementias and other disabilities.
- Explore the costs and benefits of some or all of the Pioneer Homes becoming licensed as nursing homes instead of assisted living facilities to serve individuals with higher acuity levels.
- Pursue a partnership or joint venture between the Anchorage Pioneer Home and the Alaska Psychiatric Institute to serve seniors with mental illnesses and/or developmental disabilities who present with complex behavior management needs.
- Explore the appropriateness of using the Senior Outreach, Assessment and Referral (SOAR) resources to support the partnership/joint effort noted above through the training of community gatekeepers to identify vulnerable seniors and connect with them in non-traditional settings to provide assessment and referral to treatment resources.
- Promote the provision of rehabilitation services to seniors in Pioneer Homes and nursing homes by community mental health clinicians.
- Explore implementing a Program of All Inclusive Care for the Elderly (PACE) in Alaska.

### All Individuals

- Identify subject matter experts from within and outside of Alaska to consult with staff treating individuals with complex behaviors and needs. Developing a Center of Excellence in which a cadre of trained professionals not only provide services to individuals with complex behavior management needs, but also provide technical assistance and consultation services throughout Alaska would be an invaluable resource.
- Assess the feasibility of API offering some training, consultation and technical assistance to community-based providers on behavior modification and extinction techniques to treat some individuals with complex behaviors.
- Consider a State-level investment in a program such as the one offered through Quality Behavioral Solutions to Complex Behavioral Problems - QBS, Inc., (based in Holliston, Massachusetts) to provide staff training, technical assistance and care consultation services to fill the existing staff capacity and competency gaps and to build a stronger workforce for the future.
- Review the reimbursement rates to ensure necessary services are adequately funded. Rates can be effectively used to incentivize the services that are most desired and that produce desirable outcomes.
- Streamline administrative processes to reduce wait times for approvals of special plans, funding, etc.
- Invest in workforce development e.g., training and career opportunities for direct care staff who work with individuals with complex behaviors, building workforce competence and confidence.
- Develop a university program focused on specialty training for Master's level psychologists to meet the needs of individuals with complex, often co-occurring disorders and behavioral management needs. The program would provide education in assessment, behavioral analysis and behavioral interventions and management. This could be offered as a unique Master's or certificate program.

## ISSUE ANALYSIS AND OPTIONS BRIEF:

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## INTRODUCTION

In partnership with the State of Alaska - Department of Health and Social Services (DHSS) and the Alaska Mental Health Trust Authority (The Trust), the Western Interstate Commission for Higher Education (WICHE) prepared this issue analysis and options brief to assist DHSS in developing and understanding the options available to meet the needs of persons who are now being placed out-of-state or are at risk for out-of-state placement due to complex behavior management needs and who pose an extreme risk of serious self injury or assaultive behavior resulting in injury to others.

**The individuals targeted** for this Project were Trust beneficiaries (persons with a developmental disability, mental illness, Alzheimer's and other dementias, or other cognitive impairments or chronic alcoholics with psychosis) who experience one or a combination of disorders and are difficult to place and serve within the State of Alaska, due to their complex behaviors.

**The challenge** noted at the onset of this Project, the lack of an Intermediate Care Facility for the Mentally Retarded (ICF-MR) and other intensive resources to address the needs of the targeted population in Alaska was clearly recognized by all engaged stakeholders. Alaska does not currently have a safety net to safely provide treatment services for some individuals, regardless of age, with disabilities and complex behaviors. Two years ago, Alaska did not have any individuals with developmental disabilities placed out of state in ICF-MR facilities because of behavior management issues. As of June 2009, there were eight (8) individuals placed out of state because of complex behaviors with seven (7) referrals pending and the number continues to grow, as does the need for agreements with more states to serve these individuals. A combination of State and Medicaid dollars cover most out-of-state placement and treatment costs at a rate of approximately \$500 per day. These funds also cover the travel costs for the individuals and escorts to a placement facility. However, funds are generally not available to support family members and significant others to travel to visit their loved ones. Group home and other intensive services provided in Alaska cost approximately \$300 - \$700 per day.

In order to develop this Issue Analysis and Options Brief, the WICHE Mental Health Program staff examined relevant literature, available data and reports from Alaska and other states, and conducted key informant interviews as a means to clearly articulate the issue for Alaska and to identify potential solutions. This process included an examination of models from other states where cost effective alternatives to ICF-MRs have been successfully employed. In addition, a survey was developed to capture client-level data about individuals who represent the target population. Findings from this survey helped identify the clinical presentations of these individuals and assisted with determining the placement barriers and resources needed for successful treatment in Alaska. Additionally, WICHE examined and reported upon Medicaid options used effectively by other states to fund services for the target population.

## OVERVIEW OF PROJECT METHODS

A Project Workgroup on Intermediate Care Options was formed in February 2009 to define the scope of the task and provide guidance and input throughout the six-month process. The membership of this workgroup included:

| Name               | Agency                         |
|--------------------|--------------------------------|
| Marcy Rein         | Senior & Disabilities Services |
| Steve Williams     | AK Mental Health Trust         |
| David Cote         | AK Pioneer Homes               |
| Ron Adler          | AK Psychiatric Institute       |
| David Frain        | Anchorage Pioneer Home         |
| Melissa Stone      | Behavioral Health              |
| Stacy Toner        | Behavioral Health              |
| Vickie Wilson      | Fairbanks Pioneer Home         |
| Richard Nault      | Office of Children's Services  |
| Joanne Gibbens     | Senior & Disabilities Services |
| Rebecca Hilgendorf | Senior & Disabilities Services |
| Dennis Mohatt      | WICHE Mental Health Program    |
| Debra Kupfer       | WICHE Mental Health Program    |

Workgroup meetings with conference call capacity occurred throughout the project timeline. These meetings were used to identify the target population and key stakeholders, share information, discuss data and information gathering strategies, and guide overall project activities.

WICHE staff interviewed the workgroup members in addition to key informants who were identified by the workgroup. (See Appendix I for the list of persons contacted.) Interviews occurred between March and May of 2009. Most of these interviews occurred face-to face in Anchorage, Fairbanks and Juneau. WICHE staff also traveled to Pocatello Idaho, where some individuals in out-of -state placements currently reside. The following facility visits occurred during this Project:

- ◇ Alaska Psychiatric Institute
- ◇ Pioneer Home - Anchorage
- ◇ Pioneer Home - Fairbanks
- ◇ Assets, Inc. - Anchorage
- ◇ Boys and Girls Home – Fairbanks
- ◇ Hope Community Resources, Juneau
- ◇ Belmont Care Center - Pocatello, ID
- ◇ Crestview - Pocatello, ID

Another key piece to collecting information for this project included the gathering of de-identified demographic, clinical, functioning and placement information for the specific at-risk individuals identified



by the Workgroup. A case manager or other identified person close to the individual completed an on-line survey on the identified individuals in the target population. Along with information from the key informant interviews, these survey data were used to inform the service continuum needs and gaps for this project.

WICHE also engaged three subject matter experts Kim Jensen, Colorado Department of Human Services, Cathy Anderson, Consultant from Nebraska and Gary Sappington of the Oregon Technical Assistance Corporation to share their experiences with managing difficult to place persons with complex behaviors. These experts participated in an interactive forum followed by a Workgroup meeting in Anchorage June 2009. Information from this discussion helped inform the potential strategies and options identified in this report.

Forty-five individuals attended this interactive forum. The list of stakeholders who participated in this meeting can be found in Appendix II. Cathy's presentation addressed quality management and the Centers for Medicare and Medicaid Services' Quality Framework as a model to consider when developing and expanding programs. This model includes design, discovery, remediation, and improvement based on identified quality indicators and activities. Her presentation also covered active treatment as defined in 42 CFR 483.440 - Aggressive, consistent implementation of a program of specialized and generic training, treatment and health services. This discussion stressed the need to provide active treatment to receive federal reimbursement for Medicaid and Medicare funded services. Other areas covered included the need for qualified providers, staff competencies, and evidenced-based practices for individuals with co-occurring developmental and mental health disorders. The last part of her presentation covered approaches used by other states to serve individuals with co-occurring disorders and complex behavior management needs. A summary of this information is included in the Highlights ~ Other States' Program and Medicaid Options section of this document.

Gary's presentation, *Growing Resources in Oregon* covered the six capacity building domains used in Oregon to address capacity issues related to serving individuals with complex support needs. These six domains included; 1) Personnel, 2) Placement Process, 3) Housing, 4) Partnership for Specialized Resources and Ancillary Services, 5) Communication and 6) Training and Technical Assistance. Oregon's planning process focused on better coordination between the mental health and developmental disability systems, increased emphasis on smaller treatment settings, person-centered planning and skill building, and on improving access to transition services.

Kim's presentation included a discussion of Colorado's long history of supporting a community-based service philosophy for individuals with developmental disabilities. Colorado's current Developmental Disability System includes 20 privately operated Community Centered Boards (CCBs), contract providers and agencies, and three State-operated Regional Centers geographically spread across the State. CCBs are the system points of entry and case management agencies for all receiving services, including those in the State-operated Regional Centers. Historically, (since deinstitutionalization) the Regional Center clustered residences have been licensed under regulations for Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR) while the Regional Center community group homes were licensed under the Home and Community Based Services for the Developmentally Disabled (HCBS-DD) waiver. The long-term trend is for a heightened demand for all clinical needs except medical, which can increasingly be accommodated by private providers. Active treatment is a

focus for all clinical disciplines and is staffed for seven days per week, 16 hours per day. Lapses in active treatment are aggressively cited in Medicaid surveys. Service provision for persons with the most complex needs is shifting rapidly to respond to three primary changes:

- ◇ Federally-mandated revisions to the HCBS-DD waiver;
- ◇ Significant increases in the numbers of persons presenting requiring extended one-to-one supervision; and
- ◇ Intense staffing demands associated with persons with complex behavioral needs and/or co-occurring DD/MH diagnoses.

The State is required to implement federally mandated changes to the HCBS-DD waiver, which are further constraining revenues for the Regional Centers and hindering the provision of services to this population with complex needs. These federal changes include:

- 1) The removal of certain services from the waiver and their transition to the Medicaid State Plan; and
- 2) Improved financial oversight and accountability of the program, including steps to "unbundle" services and costs in the waiver program.

As part of the HCBS-DD waiver change, the Regional Centers are no longer allowed to provide medical, psychiatric and therapy services to waiver participants. The second change, improved financial oversight and accountability, has resulted in a new fee-for-service rate structure that to date is inadequate for individuals with complex, extensive treatment needs who reside at the Regional Centers. To mitigate the effects of these changes, the Regional Centers are implementing a phased transition of the community group homes to licensure under ICF/MR regulations.

Another strategy used by Colorado was the development of a workgroup of individuals from the Mental Health and Developmental Disabilities systems who worked together to create a proposal for a continuum of care for individuals with co-occurring disorders of mental illness and developmental disabilities and their families during a mental health crisis. Unfortunately, the economic downturn prevented this proposal from being evaluated for funding but is presented here as a model for consideration by Alaska.

Components of the proposed continuum in Colorado included:

- allocation of six existing inpatient psychiatric beds at the Colorado Mental Health Institute;
- 6 bed Diagnostic Treatment Center (DTC) in the DD system with 24 hour staffing;
- 6 bed Community Centered Board group home; and
- Clinical Evaluation and Response Team (CERT) that follows the individual through the treatment continuum (including 4.0 FTE - two psychologists, a social worker / counselor, and a clinical behavioral specialist).

Although this proposal has not been able to move forward, members of the workgroup noted above continue to hold monthly meetings to review caseloads at the facilities, plan for future transitions to the least restrictive setting and to reduce barriers between the systems in order to improve services for persons with co-occurring diagnoses.

## HISTORICAL OVERVIEW AND HIGHLIGHTS OF RELEVANT ALASKA REPORTS, PLANS AND PROGRAM RESOURCES

The Workgroup shared numerous reports with the WICHE staff, which helped provide an overview of resources, programs, trends, current activities, and future plans. Additionally, WICHE staff conducted a literature search to find some historical information, specifically about the closure of Harborview. Below are highlights of several reports that provide some historical information as well as information about programs currently available in Alaska to serve individuals targeted for this Project - Trust beneficiaries (persons with a developmental disability, mental illness, Alzheimer's and other dementias, or other cognitive impairments or chronic alcoholics with psychosis) who experience one or a combination of disorders. Existing programs are typically able to support these individuals until the point where their complex behaviors make it difficult, if not considered impossible, to continue serving them with the available treatment and program resources, within the State of Alaska.

### Historical Overview - Harborview

#### **Department of Health and Social Services Division of Medical Assistance Internal Control over Medicaid Payments January 31, 2003<sup>1</sup>**

In November 1997 the State of Alaska closed Harborview Developmental Center; the only State-operated ICF-MR, which caused an influx of MRDD recipients in other programs and communities. In addition, Hope Community Resources closed two and converted three ICF-MR facilities into group homes during a three-year period, 1996 to 1998. Hope's ICF-MR residents were transferred to Home and Community-Based waivers and placed in other facilities.

#### **A Nationwide Study of Deinstitutionalization and Community Integration - A Special Report of the Public Policy and Legal Advocacy Programs - June 2004<sup>2</sup>**

Harborview Closure Information:

- There were no admissions to Harborview after 1988, and by 1994, it was felt that anyone could be served in the community. A few people, with complicated service needs, did not leave until 1997 in order to have the time to build appropriate assisted-living homes.
- There was a gradual elimination of the institutional budget. The period for closure was approximately two years.
- By the time of the final closure, there had been six years to demonstrate that people could live in the community. Because Alaska is 75% rural and over 50% Alaska Native, it was important to serve people in the communities where they live.
- Alaska has no community ICFs-MR, no institutions, and sends no one out of state, even though the waiver requires them to offer the alternative of going to an institution. (A few individuals have been sent out of state for short-term treatment when such treatment is not available in the state.)

#### Harborview Closure Opposition:

- A few families remained fearful of transitioning their relatives into the community. A few neighbors also expressed opposition to having assisted living nearby. However, in general, there was minimal opposition to closure.
- Unions had previously been active in trying to work with Harborview employees, who had expressed dissatisfaction with the working conditions. By the time the decision was made to close Harborview, the union was no longer strongly adversarial.
- No one lost a job because of the closure. There were special retirement incentives and relocation packages offered by the state. People who transferred into another state job were allowed to retain seniority, sometimes even bumping others from potential jobs.
- Many people working in the institution were transient workers who merely left once their jobs were eliminated; others were married to people with good jobs, and so they stayed in Valdez. Only about 20% of the employees took advantage of benefits and early retirement incentives.

#### Harborview - Transition and Community Living:

- Families met with providers at “fairs” to evaluate what was available and how it could satisfy the needs of their family members. Individuals were allowed to move anywhere in the state; however, they often ended up in the Anchorage area because of inadequate services in their community of first choice.
- Many at Harborview were incapable of participating fully in the planning process, so family advocates participated. In the absence of family, state and institutional staff, together with the resident, determined what was in the individual’s best interest. During this transitioning process, out-of-state guardians could transfer guardianship to the Office of Public Advocacy (state guardian).
- The Department of Health and Social Services made a concession that everyone could be served in community settings, which was often a two-person apartment/home or one’s own home, but could include up to five people.
- Initially, the state sought to have the community staff visit Harborview. It was subsequently decided that because of the “institutional” mindset of many facility personnel, this might have a negative influence in causing future community staff to underestimate individuals’ abilities to adapt to the community. Nonetheless, the Harborview staff spent a week with receiving staff in the community to help when the individual moved out.
- There was an improvement in the functional capacity of some of those transitioned into the community.
- In 1991, the DD Program initiated “individualized” services tailored to meet the unique needs of each individual and family. This approach allowed funds to follow an individual so he or she could choose different providers, thus enhancing the person’s capacity for independence as providers attempted to deliver services in his or her hometown.
- There are care coordinators to develop a comprehensive planning team for selecting needed services. Sometimes the care coordinator works within an agency. However, there are proposed regulations to require that the care coordinator work outside the agency to prevent any conflict of interest and provide the consumer with greater flexibility to choose a new agency when displeased with services.
- There has been a concerted effort to train families, who had been previously detached from the process, on how to request and evaluate the quality of services.

- There is a centralized Waiting List in the state for assessing the relative needs of individuals who seek services.

#### Harborview - Economics:

- When Harborview closed, the state initially saved several million dollars with the conversion to waiver funds. The 60% federal match was applied to residential habilitation, environmental modifications, respite care, specialized medical equipment, and supported employment. The waiver program has since grown exponentially, with over 1,200 individuals on waivers and an additional 2,500 on Community Developmental Disability grants.
- When closure occurred, even though families were allowed to spend as much in the community as had been spent for the family member at Harborview, most did not ask for the full amount allowed when they were given choices of how to best meet the needs of the individual. However, because of the subsequent increase in administrative costs paid to the agencies, the state is now considering self-determination waivers with which the consumer can buy services directly without using agencies as intermediaries. In preparation for adopting these self-determination waivers, a study has been conducted to evaluate the average cost of each category. A subsequent study is planned on cost methodology for developing a process by which this average will be tied to individuals' needs.

#### Highlights of Previous Reports

##### **Recommendations for the Alaska Long Term Care Plan - HCBS Strategies, Inc. 2008<sup>3</sup>** (Excerpts from the Executive Summary and Recommendations)

*Alaska is one of the leading states in establishing a balance between supporting people in the community versus an institution. Alaska operates a wide variety of programs that provide long-term care services that range from institutional care to home and community-based services (HCBS)... Alaska is one of only eight states that do not have a large state facility for persons with developmental disabilities (DD) and the only state to have no Intermediate Care Facility for Persons with Mental Retardation (ICF-MR).*

HCBS Strategies, Inc.'s report had several recommendations. The recommendation categories highlighted below reflect those more likely to also affect services for the target population of this report. The numbering of these recommendations corresponds to the numbers in the Executive Summary of the *Recommendations for the Alaska Long Term Care Plan*.

1. Restructure the process for matching people with funding sources: To manage the long-term care system, the State must understand whom they are serving and be able to channel individuals to the most cost-effective service options. Thus, this is an important first step that the State must take to have a sustainable system.
4. Support populations not meeting the Nursing Facility Level of Care (NF-LOC) eligibility criteria: The NF-LOC creates a significant barrier to obtaining Medicaid Federal Financial Participation (FFP) for people with Alzheimer's Disease and Related Disorders (ADRD) and Brain Injury. Unfortunately, a lack of data and uncertain federal rules would make it irresponsible to offer a specific recommendation

regarding how to address this issue. Thus, we recommend the State engage in parallel efforts to collect necessary data to analyze the implications of changing the NF-LOC and to determine the feasibility of using the 1937 Benchmark authority for providing supports to these individuals.

5. Drawing down more Medicaid Federal Financial Participation (FFP) for the Chronic and Acute Medical Assistance (CAMA) Program and Pioneer Homes (PH): We propose pursuing an 1115 Demonstration for drawing down FFP for CAMA. To draw down more FFP for PHs, the State must first alter the asset criteria so that it matches Medicaid. We also propose several additional steps that could substantially increase FFP.

- A. Change Pioneer Homes asset criteria/priority for waiver eligible.
- B. Explore the use of the Medicaid 1937 Benchmark Plans to cover the cost of care in the Pioneer Homes for people who meet Medicaid financial eligibility criteria but do not meet nursing home level of care criteria necessary for the waiver.
- C. Start reimbursement for waiver eligible individuals sooner by either claiming reimbursement once a person selects waiver services or through an expedited process to authorize services.
- D. Increase the room and board rate or change the cost of care requirements for Pioneer Homes.

6. Improve Quality Management Process: We recommend a process that is consistent with CMS HCBS Quality Framework, which itself is based upon Continuous Quality Improvement (CQI) principles. We also propose major changes to the licensing and certification processes for Assisted Living Facilities (ALFs).

- A. Establish core performance indicators that correspond to CMS requirements.
- B. Increase capacity to routinely obtain data for indicators through the core business processes (including assessment and reassessment, care coordination notes, critical incidents, licensure reviews and investigations, Adult Protective Services (APS) investigations, provider enrollment, provider certification, and other areas).
- C. Develop core management reports for State staff, Care Coordinators, and consumers.
- D. Refine the flow of information about quality problems.
- E. Refine systemic quality management system to investigate and coordinate reaction to potential issues. Process should include cross agency and external participants, including a tribal component.

7. Restructure Care Coordination: We recommend that, where feasible, Care Coordinators be independent of services providers. We have a series of recommendations that should allow Care Coordinators to play a more central role in the quality management system. We also recommend restructuring how the State reimburses care coordination.

### **Governor's Council on Disabilities and Special Education 2006-2011 State Plan<sup>4</sup>**

This State Plan identifies the mission of the Governor's Council on Disabilities and Special Education to - *create change that improves the lives of Alaskans with disabilities*. Two of the accomplishments noted in the Plan include:

- Reduce high-cost institutional services and enable individuals to stay in their local communities using Medicaid Home and Community-Based Services (HCBS) Waivers, and

- Contain costs and increase the number of persons served through the closure of Harborview Developmental Center and decertification of Hope Cottages' Intermediate Care facility for the Mentally Retarded facilities.

The Plan also notes the following in the discussion of Political Factors.

- Alaska is the first state in the country with no public or private intermediate care facilities. Generally, the Alaska Legislature and administration are supportive of community-based services for people with developmental disabilities, but as a result of several years of level funding; only people in crisis have been selected for services.
- The ability to serve people with developmental disabilities, who also experience a mental health or substance abuse disorder, is a constant challenge. Separate funding and service providers who are not cross-trained present barriers to effective services and outcomes as well as individual and family satisfaction.
- Provider capacity and the adequate funding to meet the needs of individuals with traumatic brain injury are problematic.
- Alaska has a shortage of personnel to provide direct support services to individuals...The growth in the number of individuals requiring supports exacerbates the shortage.
- An added complication is the need for an integrated data management system that can better track the status of individuals on the waitlist, and maintain up-to-date information about their needs.

### **Developmental Disabilities Waitlist Report - December 2008<sup>5</sup>**

The Department of Health and Social Services is required (AS 47.80.130 (d) to maintain a Waiting List of individuals with a developmental disability (DD) whose needs cannot be met due to inadequate funding. Additionally, an annual report of the Waiting List information is required to be presented to the Governor and identified legislative committees. A centralized database has been established to track what services persons on the Waiting List receive, how the services relate to the individuals' self-expressed needs, and whether the services are needed immediately or sometime in the future. Efforts are underway to convert the Waiting List to a DD Registry, which would serve as a management tool for the Division of Senior and Disabilities Services. Additionally, the Developmental Disabilities Registration and Review tool was developed in FY 2007 for applicants to report their needs.

Eligibility to be placed on the DD Registry or to participate in the Community Developmental Disabilities Grant (CDDG) program requires an individual have a developmental disability as defined under the provisions of AS 47.80.900 (7). The term "developmental disability" means an individual with a severe, chronic disability that:

- Is attributable to a mental or physical impairment or combination of mental and physical impairments;
- Is manifested before the individual attains age 22;
- Is likely to continue indefinitely;
- Results in substantial functional limitations in three or more of the following areas of major life activity:
  - Self care;
  - Receptive and expressive language;
  - Learning;
  - Mobility;

- Self-direction;
- Capacity for independent living;
- Economic self-sufficiency, and;
- Reflects the person's need for a combination and sequence of special, interdisciplinary, or generic assistance, supports, or other services that are of lifelong or extended duration and are individually planned and coordinated.

The following demographic information represents the status of the DD Registry population during the State of Alaska fiscal year beginning July 1, 2007 through June 30, 2008. Since the registry is constantly evolving, these data represent the specified time period and may not reflect the current state of the registry. The historical demand for services reflects minimal variance in population, geographic distribution, and services requests over time. The following data was taken from the DS3 data management system, which is used by SDS to maintain the DD Registry.

|   |                  |
|---|------------------|
| Number of individuals on the list as of 6/30/2008             | <b>845</b>       |
| Number of individuals 22 years old or younger as of 6/30/2008 | <b>610</b>       |
| Number of individuals on the list for 90 days or more         | <b>806</b>       |
| Average length of time for individuals on the Registry        | <b>46 months</b> |

| Age Range             | Number of Individuals | Percentage |
|-----------------------|-----------------------|------------|
| 0 to 3 years of age   | 51                    | 6.0        |
| 4 to 17 years of age  | 423                   | 50.1       |
| 18 to 21 years of age | 118                   | 14.0       |
| 22 to 64 years of age | 252                   | 29.8       |
| Over 65 years of age  | 1                     | <1         |
| <b>Total</b>          | 845                   | 100%       |

Approximately thirty percent of the individuals on the DD registry do not qualify for the Medicaid Waiver, decline services when they become available or are unable to participate for some other reason. Several hundred individuals on the list are eligible for services and not able to receive them because of resource limitations. However, an analysis of program data indicated that in FY 2008, 517 individuals (61.2%) on the DD Registry received some services through the DD grants program administered by SDS. Nevertheless, given the resource limitations, it is important that an adequate continuum of services be available to effectively and efficiently meet the needs of persons receiving services.

### **Autism Services Report<sup>6</sup>**

Information from the March 2009 Autism and Services Report prepared by Senior and Disabilities Services indicates that as of March 19, 2009, 354 individuals with autism were receiving services. Three of these individuals were receiving services out-of-state in an ICF-MR, since Alaska currently does not have the capacity to provide this level of services. The average age of these individuals was 17 years. It is estimated that 60 Alaskan children will be diagnosed as falling somewhere on the autism spectrum disorder continuum this year. National statistics put it at about 1 in 175 children.



In response to the need to identify and begin services sooner, the Alaska Autism Ad Hoc Committee formed and in 2005 wrote a five-step plan to raise awareness, to build a system of care, and to develop an educational program to meet the increased need for a workforce of Alaskan service providers to help children identified with autism spectrum disorder. Educational programs continue to be offered across the State and additional information as well as a calendar of events is available at <http://www.hss.state.ak.us/autism/>.

### **FASD/RPTC Home and Community Demonstration Project - Modeling, Mentoring and Monitoring: Alaska's focus for youth with dual-diagnoses**

Children with disabilities, such as those with Fetal Alcohol Spectrum Disorder (FASD) and those who have a Serious Emotional Disturbance (SED), are particularly difficult to identify. These youth are often misdiagnosed and are subsequently provided with treatment that is frequently ineffective. Youth with an FASD and SED stay in residential psychiatric treatment centers (RPTCs) nearly twice as long as the general population because traditional mental health treatments are ineffective due to the brain damage caused by prenatal exposure to alcohol. As these youth age, the health issues become more complex; coping and learning skills are often compromised so they are more susceptible to pregnancy, poverty, drug and alcohol abuse, incarceration and victimization.<sup>7</sup>

The FASD/RPTC Demonstration Project was launched in October 2007 with the goal of reducing the number of youth, ages 14 to 21, in RPTCs who are dual-diagnosed with FASD and SED. The Demonstration Project focuses on services that mirror the Alaska Native practices of *modeling* desired behaviors and *mentoring* children to learn their roles in a larger culture while *monitoring* the youth as the treatment is delivered. This is especially important because Alaska Natives are disproportionately represented in the target group.

The outcomes as a result of this project are expected to include:

- Accurate diagnoses and effective interventions that will reduce the number of FASD/ SED youth returning to out-of-state RPTC care and reduce the overall length of stay for the target population;
- FASD trained specialists will develop case plans specific to each child in the demonstration, based on a method of modeling, mentoring and monitoring;
- Effective treatment plans based on accurate diagnoses will reduce the service delivery costs; the target group will show functional improvement in life; and the majority of clients will receive services to their satisfaction.

The project is funded by the Centers for Medicare and Medicaid Services in the amount of \$15.4 million dollars but this does not represent new money to the state. Rather, this project allows Alaska to use Medicaid money formerly spent on residential psychiatric treatment on new home and community based services. Alaska was one of 10 states chosen for this demonstration and is the only state targeting interventions based on *modeling, mentoring and monitoring* for these dually-diagnosed 14 to 21 year olds. Our hope is that Alaska hopes to become a model for other states at the end of the five-year project.<sup>8</sup>

## Meeting Behavioral Health Needs in Alaska - Division of Behavioral Health (DBH) February 2009<sup>9</sup>

This report, *Behavioral Health Disorder Prevalence and People Served: What is this analysis telling us?* includes an analysis of available data for persons in Alaska with behavioral health disorders, reports 2006 estimates of prevalence of persons with these disorders and reports the numbers of persons served by DBH community program grantees.

"The mission of the Division of Behavior Health is to manage an integrated and comprehensive behavioral health system based on sound policy, effective practices and partnerships." The key service elements of the behavioral health system of care include prevention, early intervention, and treatment for persons with mental health and substance use disorders.

Service recipients in the target and priority populations include Alaskans who:

- ◇ Experience Mental Illness:
  - ◆ Emergency psychiatric needs;
  - ◆ Adults with serious mental illness (SMI); and
  - ◆ Youth with serious emotional disturbance (SED)
- ◇ Have Substance Use Issues:
  - ◆ Pregnant women who are IV drug users;
  - ◆ Pregnant women;
  - ◆ IV drug users;
  - ◆ Women with dependent children; and
  - ◆ Individuals needing residential and/or community-based substance abuse treatment.
- ◇ And Alaskans with:
  - ◆ Co-occurring disorders; and
  - ◆ Traumatic brain injury (disabling cognitive, behavioral, and/or emotional impairments).

Findings from this report note that prevalence rates for Alaskans are higher for mental health disorders than substance use disorders, with relatively little variation in rates across the regions. Statewide, there are unmet service needs for persons with SED, SMI, and SUD, with notably high unmet needs for the SED population. Therefore, findings from this report indicate that resources are not available to address the unmet service needs for these populations. This gap exacerbates Alaska's ability to dedicate the necessary resources to serve individuals with complex behavior disorders.

### [Highlights from State Plans in Alaska](#)

#### **Moving Forward, Comprehensive Integrated Mental Health Plan 2006-2011<sup>10</sup>**

*Moving Forward, Comprehensive Integrated Mental Health Plan 2006-2011* is the work of the Alaska Department of Health and Social Services, the Alaska Mental Health Trust Authority and other state agencies, boards and commissions. This plan was in response to a statutory requirement (AS 47.30.660).

The Comprehensive Integrated Mental Health Plan has a vision of optimal quality of life for Alaskans, especially those Alaskans who receive services under the Comprehensive Integrated Mental Health Program. By law, these recipients (also called beneficiaries) are Alaskans who have a mental illness, a

developmental disability, experience chronic alcoholism, or suffer from Alzheimer's disease or a related dementia. Also included are individuals at risk of developing these conditions — for example, children who exhibit behaviors or symptoms suggesting they may develop a mental disorder.

The Comprehensive Integrated Mental Health Plan 2006-2011 looks at the status of Trust beneficiaries in four areas: health, safety, quality of life, and economic security. Data are used to show long-term changes in these four areas. Another section of the Plan examines current service delivery and gaps in service. The Plan highlights current efforts to improve health, safety, living with dignity and economic security for Trust beneficiaries and indicates future avenues for further efforts.

#### Extent of the Problem

With Alaska data and national prevalence data, it was estimated that there are currently up to 90,000 Trust beneficiaries in Alaska. (This number may include duplications due to the nature of the data available). If those with substance use disorders were counted instead of just those who were alcohol dependent, the number of Trust beneficiaries would rise to 120,000. The breakout of the 90,000 beneficiaries includes:

- Chronic mental illness (adults): 27,600
- Serious Emotional Disturbance (youth): 17,000
- Alzheimer's Disease (adults over age 65): 4,900
- Brain injured: 10,000
- Developmentally disabled: 11,500
- Alcohol dependent: 19,000

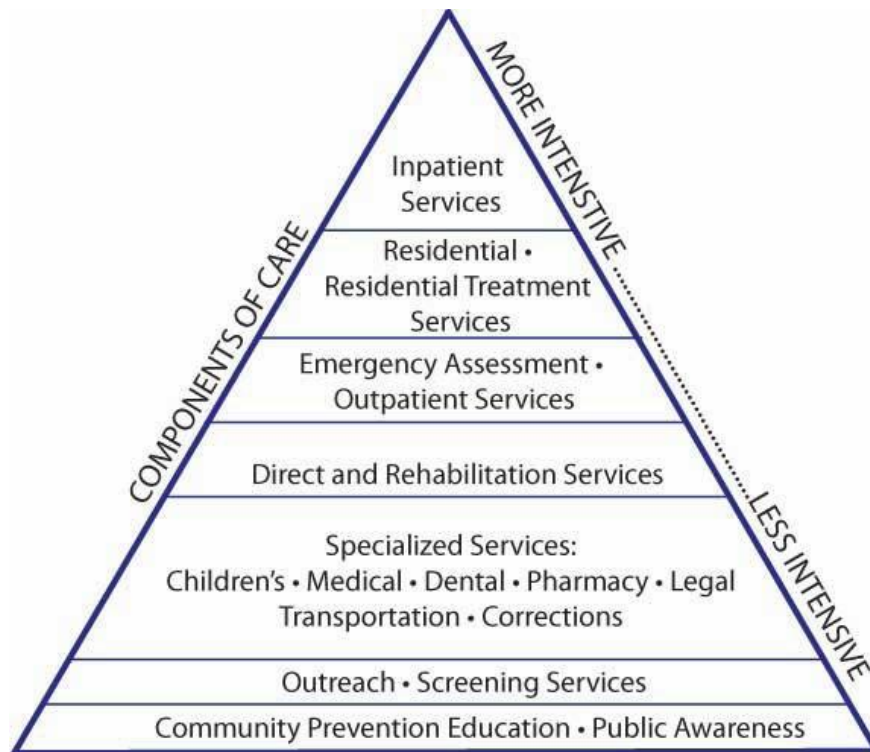
#### Current Services and Service Gaps Analysis

Services for Alaskans experiencing developmental disabilities, alcoholism or other drug addictions, mental or emotional illnesses, and Alzheimer's disease or other dementias were originally shaped and frequently compartmentalized by federal funding availability and federal program requirements.

*Advocates and program managers have long recognized that service integration is a first step toward higher quality services, increased access to services, and greater cost savings. In addition, many people experience more than one beneficiary disability during the course of their lifetimes. Simplifying and coordinating services for people with multiple cognitive or developmental disabilities is both cost effective and provides better care.*

The Trust and the Department of Health and Social Services support the components of care illustrated below, from Figure 15 of the Report, ranging from prevention at the bottom to acute care at the top for people requiring intensive care. Public education and prevention services, which reach large audiences, are listed at the bottom of the diagram. Services in the middle of the triangle are home and community-based and are used by people requiring a less intensive level of care. Although economies of scale restrict some services to urban areas, the Plan's vision is that appropriate services would be available when needed across the State. The components of care listed are only those that serve three or more beneficiary groups.

## Components of Care for Three or More Beneficiary Groups



## Moving Forward - Comprehensive Mental Health Plan 2008 Update<sup>11</sup>

### Bring the Kids Home

Bring the Kids Home is an initiative to return children with serious emotional disturbances (SED) from out-of-state residential facilities to treatment in Alaska and to keep new children from moving into out-of-state care.

Three primary goals guide the initiative:

1. Significantly reduce the number of children and youth in out-of-state care and ensure that the future use of out-of-state facilities is kept to a minimum.
2. Build the capacity within Alaska to serve children with all intensities of need.
3. Develop an integrated, seamless system that will serve children in the most culturally competent and least restrictive setting as close to home as possible.

### Recent Accomplishments

• Between FY07 and FY08, the admissions to out-of-state residential psychiatric treatment centers went down from 297 children to 202 children. This is a decrease of 32%. From FY04 to FY08 there was an overall decrease in admissions of 73%.

- *Despite the 32% decrease in admissions to Residential Psychiatric Treatment Center (RPTC) care, the recidivism rate to RPTC care remained essentially the same between FY07 and FY08 at 8.4%. This rate is significantly lower than the 20% recidivism rate during FY04.*
- During FY08 over \$2.5 million in Mental Health Trust Authority and state General Funds were put into Bring the Kids Home grants for projects to develop community based care. These grants went to 18 different agencies in communities across Alaska including both urban (Anchorage, Fairbanks, MatSu) and rural (Metlakatla, Kotzebue and Kenai) communities.

#### Recent Challenges

- Building in-home, school and community services and supports for children with serious emotional disturbances and their families.
- Developing early intervention services and treatment services, which are accessible and appropriate for young children and their families to reduce the need for higher levels of care at a later age.
- Ensuring adequate services for transitional aged youth who are soon to age out of the children's system of care.

#### Senior Behavioral Health

Senior services providers report a growing number of clients experiencing serious behavioral health needs. Aggressive behavior and substance abuse are becoming more common and more problematic in settings such as senior centers and independent-living senior housing. Pioneer Homes and assisted living facilities are seeing more individuals with serious mental illness (though often previously diagnosed) and report that they are not prepared to serve these clients in a general population setting. When behavioral health issues overlap with Alzheimer's and Related Disorders (ARD), treatment is particularly difficult to locate. Isolation, depression, and grief issues are also common among older Alaskans. Seniors often refuse to seek help from sources such as a community mental health center or a local Alcoholics Anonymous meeting because of the stigma. Special approaches are necessary to identify, make contact with, assess, and provide behavioral health services to seniors. In many communities, no programs are in place to meet these unique needs.

#### Recent Accomplishment

- Funding was received beginning in FY 2009 for the SOAR (Senior Outreach, Assessment, and Referral) Project, an effort based in DBH to use special approaches to target seniors in need of behavioral health assistance.

#### Recent Challenges

- Pioneer Homes are facing increasing pressure to find solutions in caring for residents with extreme behavioral health problems. They are not licensed to care for them, nor is API an option for long-term residential care.
- A 2007 survey of assisted living homes indicated that administrators and staff are in need of training to help them cope with aggressive behaviors by clients experiencing Alzheimer's disease or Related Disorders (ARD) or other behavioral health conditions.

#### **State of Alaska - Mental Health Block Grant - State Plan for Fiscal Years 2009-2011<sup>12</sup>** (Excerpt from the Executive Summary)

Alaska's behavioral health system includes both public and the private sectors. The public sector is responsible for serving those who do not have access to private services because of cost and/or location. Every location in the state is contained within a service delivery area. Within each service delivery area, there is a minimum of one community behavioral health program responsible for

providing services for adults experiencing serious mental illnesses (SMI) and/or needing basic substance abuse treatment services. Services for children experiencing serious emotional disturbance (SED), as well as services for less complex behavioral health needs, are also usually available.

#### FY2009-2011 Adult Plan - Major Focus

Alaska's FY2009-2011 state plan for adults experiencing SMI focuses on the integration of substance abuse and mental health services, the major transformational issue and evidence-based practices. There will also be direct attention given to the enhancement and system wide implementation of the Alaska Automated Information Management System (AKAIMS), as well as the continued development of capacity for the delivery of evidence-based practices thru an increased focus on outcome measures and performance based funding.

The Division of Behavioral Health was formed on July 1, 2003 and has been integrating the two former systems that provided community mental health and community drug and alcohol treatment into a single behavioral health system. The Behavioral Health Integration Project (BHIP) has worked extensively to develop co-occurring capability (services for individuals with both mental health and substance use disorders) throughout the behavioral health service system.

In this Plan, the Division of Behavioral Health and its planning partners renew their commitments to the importance of consumer self-determination in the planning and implementation of the behavioral health system. Consumers are represented in partnerships with their inclusion in the services supplied by traditional providers and by the funding of consumer directed programs that provide peer support services.

#### FY2009-2011 Children's Plan - Major Focus

Alaska's FY 2009-2011 State Plan for children experiencing SED concentrates on four major focus areas. These areas remain critical to the transformation of Alaska's behavioral health system for children experiencing serious emotional and behavioral disturbances and their families. The four focus areas are:

- ◇ integration of services for children experiencing co-occurring mental health and substance abuse disorders,
- ◇ reduction of out-of state and residential placements for children experiencing SED,
- ◇ increased implementation of evidence-based practices, and
- ◇ system accountability.

The overall goal for the children's plan is the increase of in-state quality of care and capacity in order to continue the reduction of out-of-state placement of Alaska's children. The reduction of out-of-state and residential placements also requires systemic restructuring and change to move resources from a residential system that is over-utilized to a community-based system that is slowly growing.

To succeed, Alaska must continue to build residential and community-based services including tribal behavioral health care. Goals for FY09 through FY2011 include developing residential and community based placements (residential treatment), group homes, treatment foster care, and increasing the availability and sophistication of wraparound coordination and individualized services to keep children at home and/or living independently or semi-independently. *To increase in-state capacity and serve the children currently referred to out-of-state care Alaska must ensure that services are effective for children with complex and multiple needs, often including co-occurring conditions and highly challenging presentations.* FY09 through FY2011 goals include increasing use of evidence-based practices (EBP) and providing resources for more effective service delivery models. This expectation

for the implementation of EBP principles and best practice models is integrated into DBH grant requirements as well as the Bring the Kids Home and Community Based Capacity Enhancement grant requirements. DBH will support providers with continued training and technical assistance to support service delivery.

### Highlights of Programmatic Resources

The following section provides information about the current Medicaid waiver programs in Alaska and highlights of some of the programs and resources available to Alaskans with disabilities and special needs. The intent of this section is to illustrate the variety of programs and services that currently exist in the State and is not intended to imply that these are the only or best programs and services that are available.

#### **Alaska's Medicaid Waiver Programs<sup>13</sup>**

Waivers provide services that are partially paid by the federal government. In order for services to be paid for through a waiver, specific Medicaid waiver eligibility guidelines through the Division of Public Assistance and Level of Care (Appendix III) through the Division of Senior and Disability Services must be met. This level of care means the applicant needs the same services that would be provided in an institution serving people with mental retardation and developmental disabilities, or a nursing home.

If a person meets the strict disability guidelines, his or her income is separated from the family's income, thus making him or her eligible for Medicaid and other support services. The purpose of waivers is to keep individuals with disabilities in their home communities and out of institutions, hospitals, and nursing facilities.

- Home & Community Based (HCB) Waiver Programs:
  - Older Alaskans (OA)
  - Mentally Retarded/Developmentally Disabled (MRDD)
  - Children with Complex Medical Conditions (CCMC)
  - Adults with Physical Disabilities (AP)

#### **Hope Community Resources, Inc.<sup>14</sup>**

Hope Community Resources, Inc. (Hope) is a private, not for profit agency operating in the state of Alaska. Incorporated in 1968, they are the largest and only statewide provider of services to individuals who experience a disability. Their main administrative office is located in Anchorage (South Central Region) with regional offices in Dillingham (Bristol Bay Region), Kodiak (Kodiak/Aleutian Region), Juneau (Southeast Region), Soldotna (Kenai Peninsula Region), Seward (Resurrection Bay Region), Wasilla (Mat-Su Region) and Barrow (North Slope Region).

Hope's goal is to offer supports to any individual who has been selected for services by the Division of Senior and Disability Services, within available resources. Hope also states that they practice a "no-discharge" policy through which families and individuals have the security of knowing that when they select Hope for their supports, Hope will never require them to leave on an involuntary basis. Through these two practices, they believe that families and individuals find the security that has often been missing in their lives.

In May of 2009, Hope was managing 40 individuals on Home and Community Based Waivers in the Southeast Region. Approximately two-thirds of the individuals have a co-occurring developmental disability and mental health disorder. Hope has noticed an increased level of need with new referrals; including individuals with difficult to manage complex behaviors. Efforts are underway for them to develop the capacity and competency to offer a specialized behavioral management group home. They plan to use a team intervention approach offering early intervention redirection, crisis avoidance, and behavior management.

### **Assets Inc.**

Assets Inc.'s overall purpose is for individuals with disabilities to thrive in and contribute to their community. Their Supported Living Services began in 1984, followed by Employment Services in 1986. Supported Living services involve a combination of skill building, coaching, and resource coordination, assisting individuals to live in their own homes. Supported Employment assists individuals to obtain and retain employment within local businesses. In addition to providing a labor force through contract services, Assets Inc. also provides foster care and adult assisted living services.<sup>15</sup>

Assets Inc. serves adults 18 years and older. Currently approximately 80% of their population has a co-occurring mental health and developmental disorder and the remaining 20% has only a diagnosis of a serious mental illness.

The Department of Corrections is a contractual partner with Assets Inc., which helps cover expenses for extra staff when needed and supports some community transition services, which begin when individuals are in jail.

### **Arc of Anchorage<sup>16</sup>**

The ARC of Anchorage helps Alaskans with developmental disabilities, behavioral health concerns or deafness achieve lives of dignity and independence as valued community members.

Short Term Assistance and Referral (STAR) - Provides information about the services available and connects people with the resources they need. Helps families apply for funding from the State of Alaska. Helps find solutions during crises and emergencies.

Care Coordination - Assists people with Medicaid waivers and their families learn about and choose among services, based on their needs and goals, then monitors implementation of the plan.

Community Living Services - Provides support that encourages independence and participation in the community, allowing adults with developmental disabilities to live on their own, with roommates, and/or staff. Also offers in-home assistance and respite care for children with developmental disabilities or complex medical conditions who live with their families or with foster families.

Behavioral Health Services - Serves children and adults with a diagnosis of behavioral health disorder and/or other related disorders with options for therapy, building life skills, finding work or a place to live, and strengthening social skills.



Supported Employment - Helps adults find and keep jobs in the community and assists each individual to gain the daily living and on-the-job skills necessary for successful employment.

Recreation Services - Offers older teens and adults the opportunity to learn new skills, make friends, and participate in a wide variety of community activities.

Nursing Services - Trains parents and care providers so they can create a safe, healthy environment that allows children with complex medical conditions to leave the hospital and live at home with their families. Provides intensive active treatment for adults to avoid institutionalization and continue living at home and participating in community life.

Deaf and Hard of Hearing Center - Promotes independence through consumer services, independent living, communication, and vocational skills. Also provides daily support in a residential setting for students attending the State School for the Deaf and Hard of Hearing. The Interpreter Referral Line (IRL) schedules American Sign Language interpreters for meetings. A two-week summer camp welcomes young people who are Deaf or hard of hearing.

Substance Abuse Treatment - Helps adults who experience a developmental disability and a behavioral health disorder recover from substance abuse in a residential setting. Job training and independent living skills help prepare for the transition at the end of treatment.

ArcTrust - Supplemental needs trusts offer families a way to plan for the financial future of their loved ones who experience disabilities without affecting eligibility for public benefits.

### **Fairbanks Resource Agency<sup>17</sup>**

Fairbanks Resource Agency is a non-profit Alaska corporation dedicated to assuring that Interior Alaskans with disabilities and their families have equal opportunity to be fully integrated into the community where education, employment, housing, recreation and family support services are available in the same places, at the same times and with the same respect afforded any member of the community. They provide employment, residential senior, family and short-term (Short-Term Services Program - STAR) services, in addition to care coordination and public education.

### **Alaska Psychiatric Institute (API)<sup>18</sup>**

Alaska Recovery Center is Alaska's only state psychiatric hospital operated under the aegis of the Alaska Department of Health and Social Services. The hospital has an 80-bed capacity and operates five patient treatment units:

- ◇ Susitna Unit, 24 bed adult acute care;
- ◇ Katmai Unit, 26 bed adult acute care;
- ◇ Chilkat Unit: 10 bed adolescent acute care;
- ◇ Taku Unit, 10 bed medium security forensic; and
- ◇ Denali Unit, 10 bed adult long-term care.

The hospital has transformed the culture of the treatment units to that of a recovery paradigm and operates a successful 'Recovery Mall' with a computer lab and many 'classroom' opportunities for patient education. Another significant innovation is the TeleBehavioral Health Program, which extends

the clinical infrastructure of the hospital to remote-frontier areas to provide greater access to services via technology (telemedicine). In July 2009, API will launch the state pilot for the treatment of depression in primary care, 'Impact', a collaboration with the Alaska Mental Health Trust Authority, Anchorage Neighborhood Health Center and the Chugachmiuk Corporation.

### **Pioneer Homes<sup>19</sup>**

Alaska Pioneer Homes operates six licensed Assisted Living Homes for older Alaskans. These homes are located in Anchorage, Fairbanks, Juneau, Ketchikan, Palmer and Sitka. Services available include nursing, physical and emotional support; help with daily life skills, and other support services including end of life care. Many residents receive services that qualify for the Older Alaskan Home and Community-based Medicaid waiver.

Occupancy of Pioneer Homes fluctuates, but system-wide as of March 2009 there were 462 residents occupying the 508 beds, of whom 109 (23.5%) were veterans. All residents require a safe home environment, room and board, and opportunities for social interaction and recreation. Of the 462 residents, 292 require high levels of professional care available 24-hours a day. Another 143 residents need assistance with basic living skills at some time during the day, and 73 residents are fairly independent, occasionally requiring emergency assistance. There are 2,921 qualified Alaska residents on the Waiting List, which means they are over age 65 and intend to enter one of the Pioneer Homes in the future. Of these, 296 are on the Active Waiting List, needing placement when available. The current rates for the Alaska Pioneer Homes range from \$2,240 per month for housing with some assistance in making appointments and other social services to \$5,880 for the highest level of care including 24-hour supervision, extensive assistance with activities of daily living, and intermittent health care; with a five percent increase in these rates July 1, 2009. About 50 percent of Pioneer Home residents depend on the Medicaid Waiver and/or state-funded payment assistance program to pay for at least part of the monthly rate.

## HIGHLIGHTS ~ MEDICAID OPTIONS AND OTHER STATES' PROGRAMS

The following narrative includes background information about Medicaid-funded programs, residential services trends for individuals with developmental disabilities and ICF-MR alternatives.

### **Background and Summary of Medicaid Long-Term Care Programs<sup>20</sup>**

Federal participation in long-term care for persons with intellectual disabilities and related developmental disabilities began in 1965 when Medicaid was enacted as Medical Assistance, Title XIX of the Social Security Act. It provided federal matching funds from 50% to 83%, depending on each state's per capita income, for medical assistance, including Skilled Nursing Facilities (SNFs), for people in the categories of elderly, blind, disabled, and dependent children and their families.

Federal reimbursement for skilled nursing care was followed by rapid growth in the number of individuals placed in these facilities. Many of these individuals received more medical care than was clinically necessary, which was thought to be related to the federal reimbursement incentives. This led to a less medically oriented and less expensive "Intermediate Care Facility" (ICF) program for elderly and disabled adults was authorized under Title XI of the Social Security Act in 1967.

In 1971, the SNF and ICF programs were combined under Title XIX. The legislation that combined the two programs also authorized federal financial participation (FFP) for "intermediate care" provided in facilities specifically for people with Intellectual Deficits/Developmental Disabilities (ID/DD) - ICF-MRs.

Most states chose to certify their public institutions to participate in the ICF-MR program. However, over time with the growing support for community versus large institutional residential services led to the development of community-based ICF-MR facilities and clarification by the Health Care Financing Administration (HCFA, now the Center for Medicare and Medicaid Services -CMS) of how the ICF-MR level of care could be delivered in 4-15 person group homes. In 1981, HCFA issued "Interpretive Guidelines" for certifying community-based ICF-MR. These guidelines were published in the same year (1981) that Congress enacted legislation that would give even greater opportunity and flexibility to states to use Medicaid funding for community services through the Medicaid Home and Community Based Services waiver authority (Section 2176 of P.L. 97-35).

Home and Community-Based Services (HCBS) Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (P.L. 97-35), granted the Secretary of Health and Human Services the authority to waive certain existing Medicaid requirements and allow states to finance "non-institutional" services for Medicaid-eligible individuals. The Medicaid Home and Community-Based Services (HCBS) waiver program was designed to provide non-institutional, community services to people who are aged, blind, disabled, or who have an intellectual disability and related developmental disability (ID/DD) and who, in the absence of alternative non-institutional services, would remain in or would be at a risk of being placed in a Medicaid facility (i.e., a Nursing Facility or an ICF-MR).

A wide variety of non-institutional services are provided in state HCBS programs, most frequently these include service coordination/case management; in-home supports; vocational and day habilitation services; and respite care. Although not allowed to use HCBS reimbursements to pay for room and

board, all states provide residential support services under categories such as personal care, residential habilitation, and in-home supports.

Many states capitalized on incentives for placing persons with ID/DD in Medicaid certified nursing facilities; which led to criticism about the appropriateness of these placements from advocates. In 1987, Congress responded to these and other criticisms of nursing facility care through the Omnibus Budget Reconciliation Act (OBRA) of 1987 (P.L. 100-203). Provisions of this legislation restricted criteria for admissions to Medicaid reimbursed nursing facilities to admissions by those persons requiring the medical/nursing services offered. Over time, this has resulted in fewer persons with ID/DD residing in these facilities.

### **Persons Presently Not Receiving Residential Services on Waiting Lists for Residential Services<sup>21</sup>**

This section of the Residential Services for Persons with Developmental Disabilities: Status and Trends through 2004 report summarizes statistics by the thirty-six reporting states on the actual or estimated number of people with intellectual disabilities and related developmental disabilities (ID/DD) not receiving residential services who were on waiting lists for such services on June 30, 2004. Among these states, 69,250 persons were reported to be waiting for services. Estimates for the U.S. as a whole were made based on the same ratio of persons waiting for residential services to persons receiving residential services in the 15 states not reporting waiting list data as in reporting states. (Florida was, however, excluded from this basis of estimate because of its usually large and disproportionate number of persons waiting for service.) Based on reporting states on June 30, 2004, an estimated national 88,841 persons with ID/DD were waiting for residential services. Statistics from reporting states indicate that current residential services capacity would need to be expanded by an estimated 21.1% to create residential services for all the people presently on waiting lists for them. This does not include growth in specific types of services needed to serve persons wishing to move from one type of residential setting to another (e.g., a large facility to a community residence).

Six states (California, Hawaii, Idaho, North Dakota, Rhode Island and Vermont) reported having no persons with ID/DD who were not presently receiving services who were known to be waiting for residential services. In contrast, fourteen states reported waiting lists of such length that their residential services programs would need to be expanded by more than 25% to accommodate presently identified needs.

Alaska reported a needed growth in residential services of approximately 109% to match the needs of this population. These data clearly identify a residential service gap for individuals with developmental disabilities, which is only compounded when these individuals present with complex behavioral needs.

### **Examples of Programs and Services from other States Developed to Address Individuals with Disabilities, Special Needs and Complex Behaviors**

**Alabama Comprehensive Support Services** were developed as a result of facility closures in 2004. Mobile teams go onsite to address crisis situations and there are also 24 hour phone consultation teams available. Teams consist of Psychologist (PhD), Masters Level Psychologist, Case Manager, Psychologist Assistants, Primary Care Physician, Psychiatrist and Dentist. Services include:

- Consultation regarding individuals with severe behavioral problems;
- Assistance with developing Behavioral Support Plans and Program Review Committees;
- Training in behavioral analysis regarding specific individuals and/or workshops on particular topics;
- Assistance with assessment of psychiatric symptoms;
- Consultation for individuals who have numerous psychotropic medications;
- Assistance in developing medication reduction plans;
- Consultation for individuals on psychotropic medications who have no community psychiatrist;
- Monitoring of psychotropic medication effectiveness;
- Provide direct dental care services when dentists who are experienced with MR/MI patients are not available in the community; and
- Assistance when referrals are needed for specialized dental procedures.

**The California-Mental Health Department Collaboration** is the result of the California Welfare and Institutions (W&I) Code, Section 4696, in which county mental health departments and Regional Centers are required to collaborate, meet on a yearly basis, and establish a Memorandum of Understanding (MOU) that outlines service delivery.

**The Connecticut-Effective Interagency Collaboration** includes a framework for collaboration between its separate mental retardation and mental health agencies that is proving to be successful. While barriers still exist in terms of adequacy of financial resources and a lack of clinically trained and available practitioners, significant strides have been made in the area of access to mental health inpatient services and following up on the provision of community outpatient services.

**The Kansas-Dual Diagnosis Treatment and Training Service (DDTTS)** is designed to serve people whose diagnosis includes a psychiatric disorder such as schizophrenia or depression and a developmental disability such as mental retardation or autism. Referrals are made through contact with local Community Developmental Disabilities Organizations (CDDOs). The DDTTS is comprised of 27 staff, including six Ph.D. psychologists, a master's level psychologist, a Qualified Mental Retardation Professional, and a nurse, that provide both community outreach and inpatient services.

For the community outreach portion of the service, DDTTS teams go out to communities anywhere in Kansas where CDDOs or provider agencies have requested help serving an individual with dual diagnosis. They conduct a behavioral analysis of the problem, which consists of one to four days of observations and meetings with local support team members, then based on the analysis, develop recommendations for improving or maintaining support strategies for the individual. Regular follow-up consisting of data collection, regular telephone calls, and on-site visits is provided for up to six months after the consultation. DDTTS staff also train local caregivers such as families, Community Mental Health Centers, schools, or Community Developmental Disabilities Organizations, to sustain the individual's treatment and staff also work with other agencies to maintain the individual in his or her preferred community placement. The DDTTS program is not set up as a crisis intervention team but rather as a longer-term training and treatment program.

**The Maine-Crisis Team** consists of three regional crisis teams with state employees who provide support to persons in crisis and their families, including triage, telephone and face-to-face safety assessments, supportive counseling, crisis plan development based on the results of an assessment of the person's immediate safety and support needs, and follow-up. Services are

delivered in a timely manner, on average within 30 minutes or less, with availability 24 hours a day, seven (7) days a week.

The teams consist of Crisis Team Case Managers and Mental Health Worker III positions, directed by a Crisis Team Supervisor and supervised by the Mental Retardation Team Leader for that region. Teams have access to personnel capable of processing involuntary hospitalization.

Whenever possible, a person in crisis is seen and stabilized in his or her residence. Interventions take place in a variety of settings, including private residences, group homes, work sites, shelters, schools, mental health agencies, and hospital emergency departments. To assure safety for persons in crisis and staff, crisis intervention counselors determine the appropriate site for the intervention, may request the services of law enforcement to be present or to transport the consumer to a safer location, and do not act alone in a questionable situation without law enforcement backup and reliable technical support (e.g. cell phone, pager, etc.).

Teams are housed in regional offices and team members play an integral role in supporting the case management system. Crisis Supervisors are part of the regional management teams and participate in Mental Retardation staff meetings. Case managers are encouraged to contact crisis teams directly when issues are occurring that they feel require the support, intervention, or monitoring by the crisis teams. The team can be accessed through the statewide crisis number that then directs the caller to the appropriate area call center. Once information is taken by the call, centers the crisis teams are contacted and respond to the individual.

**The New Mexico-Pilot Project Clinic** is the collaboration of a state-county-provider task force. New Mexico developed a service delivery model that utilizes clinic sessions and promotes best practice concepts from the fields of developmental disabilities (DD) and mental illness (MI). Clinics occur at the local provider agency and are scheduled for a half-day, depending on the reasons for the individuals' visits. A typical clinic session for a new individual usually runs about two hours and begins with a visit from the local mental health center and University psychiatrists; other professionals may be included in the visit when appropriate. This "intake" team then presents relevant issues and findings to the full clinic interdisciplinary team in order to identify appropriate medical, psychiatric and programmatic treatment. When appropriate, an individual may return to the clinic for a follow-up session; these sessions may or may not include the individual, and typically run about an hour in length.

Referrals are accepted for any individual who is 18 years of age or older, has the dual diagnoses of developmental disabilities and mental illness (DD/MI) or a mental illness and is suspected of having a developmental disability, lives within the geographical area served by the replication site, and would benefit from the services of the DD/MI clinic. The individual can be seen regardless of whether or not they currently have a funding source.

Exit criteria for individuals served through the DD Waiver includes: 1) Clinical Coordinator coordinates with DD Waiver case manager and confirms the transfer of recommendations to the DD Waiver case manager; 2) Clinical Coordinator makes one additional follow-up call—according to the timeline set out in the recommendations (2-8 weeks depending upon circumstances) to determine status of follow-up; 3) If Clinical Coordinator determines that follow-up by DD Waiver case manager has been insufficient,

Clinical Coordinator will immediately report the need for technical assistance (TA) to the NE Regional Office of the Developmental Disabilities Supports Division (DDSD); 4) Clinical Coordinator will briefly summarize the case at the next Pilot Project Clinic and close the case.

**The New York Office of Mental Health (OMH)/Office of Mental Retardation and Developmental Disabilities (OMRDD) Collaboration** began in November 2007, when Commissioners Hogan and Ritter held a video conference with the OMH Regional Directors and OMRDD Developmental Disabilities Services Offices (DDSOs) on issues related to dual diagnosis. The DDSOs and OMH Field Offices established collaborative teams, including managers and clinical staff, county mental health staff, and county community services personnel as deemed appropriate locally. The teams submitted their initial status reports at the end of November 2007 and a second report in March 2008. The reports include:

- Identification of team members;
- Identification of known persons with challenging service needs with an initial emphasis on, but not limited to, persons in inappropriate settings and/or who require cross-agency solutions;
- Identification of unique/successful collaborative activities or services and systems issues or barriers to effective coordination of services for persons with dual diagnosis and who are eligible to receive both OMH and OMRDD services; and
- Identification of existing collaborative models that may be appropriate for expansion or replication.

**The North Carolina Mobile Crisis Management** involves all support, services and treatments necessary to provide integrated crisis response, crisis stabilization and crisis prevention. The services are available at all times, 24/7/365, and are part of the state's Community Alternatives Program Mental Retardation/Developmental Disabilities home and community-based waiver.

Crisis response provides an immediate evaluation, triage and access to acute mental health, developmental disabilities, and/or substance abuse services, treatment, and supports to effect symptom reduction, harm reduction, and/or to safely transition persons in acute crises to appropriate crisis stabilization and detoxification supports and services. These services include immediate telephonic response to assess the crisis and determine the risk, mental status, medical stability, and appropriate response. Mobile Crisis Management also includes crisis prevention and supports that are designed to reduce the incidence of recurring crises. These supports and services should be specified in a recipient's Crisis Plan, which is a component of all Person Centered Plans.

Mobile Crisis Management services must be delivered by a team of practitioners employed by a MH/SA/DD provider organization that meets DMH provider qualification policies and procedures and state requirements. The team of individuals must include either be a nurse, clinical social worker or psychologist and one of the team members must be a Certified Clinical Addiction Specialist, Certified Clinical Supervisor or a Certified Substance Abuse Counselor (CSAC). Each organization providing crisis management must have 24/7/365 access to a board certified or eligible psychiatrist. The psychiatrist must be available for face-to-face or phone consultation to crisis staff. A Qualified Professional (QP) or Associate Professional with experience in developmental disabilities must be available to the team as well. Paraprofessionals with competency in crisis management may also be members of the crisis management team when supervised by the QP.

**The North Carolina Behavior Consultation Services** in their HCBS Waiver provide waiver participants with assessment, treatment, consultation, support and training in behavioral procedures and techniques that are designed to decrease maladaptive behaviors while increasing positive alternative behaviors. This service is intended to assist participants in acquiring and maintaining the skills necessary to live independently in their communities and avoid institutional placement. Behavioral consultants provide assessment and treatment of participants and support, training and consultation to staff and, or family members or primary caregivers who support participants who exhibit maladaptive behavior that is often dangerous and possibly life-threatening, which are often complicated by medical or mental health factors. Consultation may include assessing behavior, designing a behavior intervention program, monitoring the plan and training staff, family members or primary caregivers on how to implement the plan.

**The Ohio Coordinating Center of Excellence (OCCE)** was developed upon completion of an interagency agreement between the Ohio Department of Mental Health (ODMH) and the Ohio Department of Mental Retardation and Developmental Disabilities (ODMRDD), which specified the creation of a Coordinating Center of Excellence (CCOE), as well as cross training of personnel. The purpose of the CCOE is to assist Ohio in addressing the systemic and clinical treatment needs of individuals with dual diagnosis. The Ohio Mental Illness/Mental Retardation and Developmental Disabilities CCOE was jointly funded by the ODMH, ODDC and ODMRDD as a three-year project and has already an impressive record of accomplishment of accomplishments. The ultimate goal of CCOE is to provide services to all 88 Ohio counties, and already, contracts have been established with the MR/MH Boards in all counties and with relevant government departments and community organizations and programs are in the initial stage in 39 counties. The CCOE has developed a protocol for establishing local Dual Diagnosis Teams, and so far, such teams are under development in 16 counties.

**The Oregon - Alternatives to ICF-MRs** were developed when Oregon closed institutions for individuals with developmental disabilities. They set up a small network of state operated group homes to serve individuals who are medically fragile or individuals with the most severe behavioral challenges, including criminal behaviors. They also set up regional crisis teams and specialized contracts to help triage challenging cases.

**The Tennessee-Community Inclusion Project** engaged the Tennessee Department of Mental Retardation Services (DMRS), Department of Mental Health and Developmental Disabilities (MHDD) and the Tennessee Council on Developmental Disabilities (DD Council) in the development of the Community Inclusion Project (CIP) to provide outpatient evaluations and staff training for individuals with dual diagnoses moving from Middle Tennessee Mental Health Institute to the community. The CIP also identified solutions for the many barriers faced by many people with dual diagnoses and their care providers. The ultimate goal of the CIP was to provide a framework for guiding collaborative service delivery among behavior analysts, psychiatrists, and medical professionals.

The work of the CIP led to the development of the Tennessee DMRS Intensive Consultation Team (ICT) in 2004. The ICT was charged with identifying resources that directly or indirectly serve crisis situations for people with dual diagnoses. Each region in Tennessee is assigned a psychology director, associate director, and behavior management specialist responsible for developing a response network



that prevents problem behaviors from jeopardizing community placement. This includes training service providers about how to manage behavioral and mental health issues.

Mobile Crisis – Before a person can be admitted to an acute care facility, an evaluation must be conducted to determine whether the person meets federal and state criteria for hospitalization. In Tennessee, a crisis team called Mobile Crisis provides 24-hour emergency services to assess a person's capability of hurting themselves or others. Services are focused on assessment and resolution of the potential crisis in the community setting. If hospitalization is deemed appropriate, the crisis team determines where the consumer should go. If possible, the person is treated in the home. If not, they are institutionalized for a brief period to stabilize the crisis.

When a person is admitted for a crisis, the Intensive Consultation Team (ICT) is notified. The ICT model is based on primary, secondary and tertiary prevention of problem behavior. Primary prevention includes activities such as establishing an advisory group to inform the ICT about service issues, identify resources to support people in crisis, and tracking incident data related to the consumer and their residential provider agency. The information obtained in the primary prevention phase is used to refine service delivery. Secondary prevention includes direct training for agencies about mental health and behavioral issues as they relate to dual diagnoses. This may entail refinement of a crisis prevention plan aimed at reducing recidivism and unnecessary use of emergency response systems. Tertiary prevention includes consultation with chronic and acute care facilities to foster a support system that reduces the likelihood of recurring crises and recidivism. The major function of the ICT is to assess the need for additional services that may prevent crises from occurring in the future. The ICT is also helpful for ensuring continuity of care when the person transitions from the inpatient facility to the community.

In addition to Mobile Crisis Teams responding to crisis situations, DMRS has formed consultation teams in each Regional Office. These teams develop a network to help prevent, manage and respond to behavioral crises. The ICT works with the teams' behavior analyst, psychiatrist, and support coordinator to collaborate regarding resources they need to provide adequate care for the consumer.

**The Washington - State Collaboration Work Plan** was developed in 1999 by Washington's Division of Developmental Disabilities (DDD) and Mental Health Division (MHD) to better serve the dual diagnosis population through a three-phase framework, described below.

#### Phase 1a: Prevent Hospitalization

- Systematically educate and collaborate at the local level regarding individuals nearing crisis: teleconference or videoconference might be most cost effective for collaboration.
- Establish liaisons among local mental health and developmental disabilities and state hospitals to serve as single points of contact to improve coordination. Establish a process for the liaisons to communicate about specific individuals prior to hospital admission, including quarterly liaison meetings.
- Hold quarterly local network meetings to address continuous quality improvement issues and conduct trainings.
- Develop a statewide, cross-system DDD / MHD training plan. Explore using blended funds to develop training plan and conduct training.
- Identify dual diagnosis expertise within the DDD / MHD systems.
- Provide access to DDD behavior specialists to conduct functional assessments and develop positive behavior support plans.

- Facilitate development of crisis prevention plans through collaboration of residential, day and community DDD and MHD providers.
- Provide timely access to community respite beds for individuals when appropriate – individual must have existing community placement and funding to access respite beds.
- Increase individuals' access to psychiatrists with dual diagnosis expertise.
- Increase DDD and MHD contracts with registered nurse practitioners to monitor medications.

**Phase 1b: During Hospitalization**

- Develop a habilitative mental health care program.
- Create a specialized developmental disabilities treatment team including PhD Program Manager, DD/MH Psychiatrist, DD Psychologist and Social Worker. Consulting Psychiatrist with dual diagnosis expertise should be available to hospital staff.
- Expand Day Program and Weekend Program – hours and services.

**Phase 1c: Planning for Discharge**

- Ensure discharges are timely and linkages are made with appropriate community services.
- Following admission, convene a team that includes person, family, residential provider, DDD, RSN liaison, hospital staff and others as appropriate who will meet regularly to: develop individualized discharge criteria; begin immediate placement planning at time of admission; develop a long-term support plan; develop post-discharge plans; identify resources for employment opportunities, day programs and other activities; and develop a written crisis plan.
- DDD and MHD should develop a database for monitoring key variables and movement of individuals through the DDD and MHD systems.

**Phase 2: Building a Community Infrastructure**

- Enhance crisis prevention through improved capacity for developing functional assessments and positive behavior support plans. Add 5 staff psychologists and/or behavioral specialists to DDD regional offices for this capacity and make individualized technical assistance available to individuals and families during the assessment process.
- Include a Crisis Response Plan within each Individual Treatment Plan.
- Crisis Intervention – add 18 voluntary, short-term use dual diagnosis diversion beds to the state. Explore successful crisis intervention models.
- Ensure that regional staff collaborate and coordinate to allow individuals access to diversion resources.
- Support the development of two (2) new crisis triage centers, one in Eastern WA and one in Southwest WA.
- Expand Residential and Day Treatment Program Capacity through providing funding to serve 70 individuals in intensive tenant support (ITS) services in the community.
- Determine and implement appropriate caseloads for case managers.
- Develop a process for equitable allocation of technical assistance dollars amongst DDD and MHD regions.

**Phase 3: Implement DDD Residential Stabilization / Treatment Model**

- The Residential Stabilization/Treatment Model is typically a 12-bed site, separated into two 6-bed units on the Eastern and Western sides of the state. Living arrangements and staffing patterns are adequate for protection from physical and psychological harm and freedom from restraint.
- Clear entry/exit criteria

- Behavior management and positive behavior support plans based on functional assessments
- Objective data collection
- Involvement of family and community providers in treatment plan development
- Medication evaluation and management or stays longer than 90 days.

Washington's comprehensive waiver includes Mental Health Stabilization as a service that could be provided to individuals with dual diagnosis. Mental Health Stabilization includes services that assist persons experiencing a mental health crisis and are available to adults determined by mental health professionals or DDD to be at risk of institutionalization in a psychiatric hospital without one or more of the following services:

- Behavior Management and Consultation, which includes the development and implementation of programs designed to support waiver participants using strategies for effectively relating to caregivers and other people in the waiver participant's life and direct interventions with the person to decrease aggressive, destructive, and sexually inappropriate or other behaviors that compromise their ability to remain in the community.
- Skilled Nursing Services, which are continuous, intermittent or part time nursing services within the scope of the state's Nurse Practice Act.
- Specialized Psychiatric Services, which are specific to the individual needs of the person with developmental disabilities who is experiencing mental health symptoms and may include psychiatric evaluation, medication evaluation and monitoring, or psychiatric consultation.
- Mental Health Crisis Diversion Bed Services, which are temporary residential and behavioral services provided in a client's home or licensed/certified setting and are available to eligible clients that are at risk of serious decline of mental functioning and who have been determined to be at risk of psychiatric hospitalization.

### Centers for Medicare and Medicaid Services -Program of All-Inclusive Care for the Elderly (PACE)<sup>22</sup> and Similar Programs

The Program of All-Inclusive Care for the Elderly (PACE) is a capitated benefit authorized by the Balanced Budget Act of 1997 (BBA) that features a comprehensive service delivery system and integrated Medicare and Medicaid financing. The program is modeled on the system of acute and long term care services developed by On Lok Senior Health Services in San Francisco, California. The model was tested through CMS (then HCFA) demonstration projects that began in the mid-1980s. The PACE model was developed to address the needs of long-term care clients, providers, and payers. For most participants, the comprehensive service package permits them to continue living at home while receiving services rather than be institutionalized. Capitated financing allows providers to deliver all services participants need rather than be limited to those reimbursable under the Medicare and Medicaid fee-for-service systems. Currently 30 states have a total of 68 PACE sites with not-for-profit status.

The BBA established the PACE model of care as a permanent entity within the Medicare program and enables States to provide PACE services to Medicaid beneficiaries as a State option. The State plan must include PACE as an optional Medicaid benefit before the State and the Secretary of the Department of Health and Human Services (DHHS) can enter into program agreements with PACE providers.

Participants must be at least 55 years old, live in the PACE service area, and be certified as eligible for nursing home care by the appropriate State agency. The PACE program becomes the sole source of services for Medicare and Medicaid eligible enrollees.

An interdisciplinary team, consisting of professional and paraprofessional staff, assesses participants' needs, develops care plans, and delivers all services (including acute care services and when necessary, nursing facility services) which are integrated for a seamless provision of total care. PACE programs provide social and medical services primarily in an adult day health center, supplemented by in-home and referral services in accordance with the participant's needs. The PACE service package must include all Medicare and Medicaid covered services, and other services determined necessary by the interdisciplinary team for the care of the PACE participant.

PACE providers receive monthly Medicare and Medicaid capitation payments for each eligible enrollee. Medicare eligible participants who are not eligible for Medicaid pay monthly premiums equal to the Medicaid capitation amount, but no deductibles, coinsurance, or other type of Medicare or Medicaid cost-sharing applies. PACE providers assume full financial risk for participants' care without limits on amount, duration, or scope of services.

Programs similar to PACE include the following:<sup>23</sup>

**Medicare Demonstration Waiver Authority** - Some states have requested Medicare demonstration waivers. These states have borrowed certain features of PACE including integrated Medicare and Medicaid financing, marketing, and care, as well as the PACE risk-adjusted rate for the frail elderly. In addition, demonstration waivers allow states to serve not only the frail elderly who meet a nursing facility level of care, but all persons who are dually eligible.

**Medicare+Choice** - Some plans and states have recently considered using the Medicare+Choice program as another approach to integrating care for dual eligibles. Medicare+Choice plans integrate care with Medicaid benefits without applying for Medicare waivers and plans can serve a large number of dual eligibles through a network of providers.

## FINDINGS ~ POINT-IN-TIME SURVEY

A survey was developed to capture client-level data about individuals who represent, as a sample, the target population to assist with efforts to identify the program and service needs for individuals at-risk of out-of-state placement. Findings from this survey are summarized below and include the demographic and clinical presentations of the individuals who were placed out-of-of state and those who were determined to be at-risk of out-of-state placement. Information from the survey assisted with determining the placement barriers and resources needed for successful treatment of these and other similar individuals in Alaska.

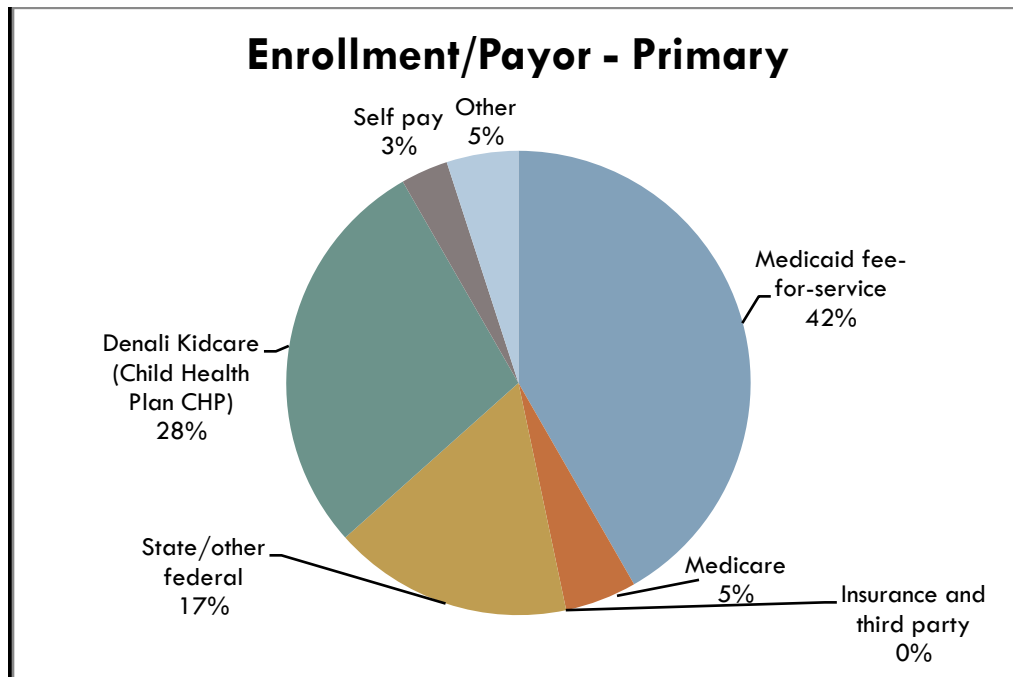
The link for this survey was distributed to staff and, or caregivers to complete on 80 individuals, 23 who were in out-of-state placements when the survey was distributed. The individuals selected for the survey were identified by the Workgroup members. The intent of this part of the project was to gain a presentation of the individuals who are at-risk of out-of state placement due to challenging behaviors. It is important to note that through the stakeholder interview process older adults with Alzheimer's and other dementias were identified as often presenting challenging behavior management issues, however these individuals have not been placed out-of-state therefore are 'under-represented' in this survey. Therefore, this population is included in the scope of this project, just not a significant part of the survey.

Sixty (75%) of the surveys were completed. A summary of the demographic information reported on the completed surveys follows.

- Age
  - 8-13 years - 12% (7 youth)
  - 14-25 years - 45% (27 transition age youth- young adults)
    - 18 youth ages 14-17
    - 9 young adults ages 18 - 22 (none surveyed were 23-25 years of age)
  - 26-55 years - 35% (21 adults)
  - 56 and more years - 7% (4 older adults)
  - Missing 1% (1 adult or older adult)
- Gender
  - 68% (41) Male
  - 32% (10) Female
- Race
  - American Indian or Alaskan Native 40% (24)
  - Asian 3% (2)
  - Black or African American 3% (2)
  - Native Hawaiian or other Pacific Islander – (0)
  - White/Hispanic 55% (33)
- Ethnicity
  - Hispanic 6.7% (4)
  - Not Hispanic or Latino 93.3% (56)
- Enrollment/Payor Source (Primary)

- Medicaid fee-for-service 41.7% (25)
- Medicare 5% (3)
- Insurance and third party – (0)
- State/other federal 16.7% (10)
- Denali Kidcare (Child Health Plan CHP) 28.3% (17)
- Self pay 3.3% (2)
- Other 5% (3)

### Enrollment/Payor - Primary



### Current Placements

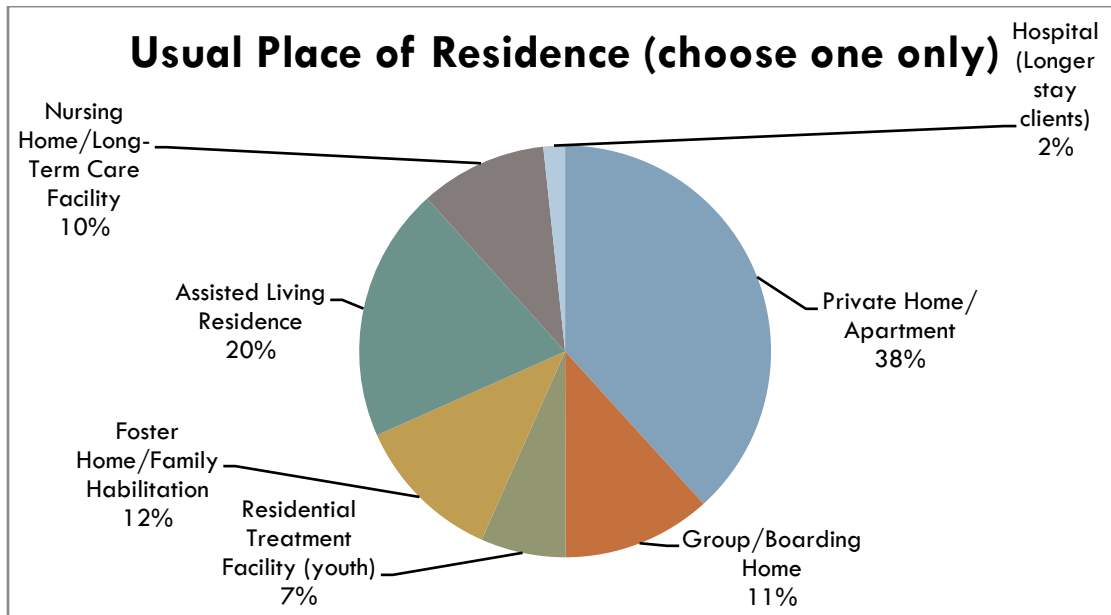
As noted previously, 23 of the surveyed individuals were in out-of-state placements - nine (9) were in Residential Psychiatric Treatment Centers, 12 were in ICF-MRs and of the remaining two, one was in a Children's Hospital and School and the other was in an out-of-state group home for boys with behavioral disorders. (The survey was available for completion during April and May, therefore was completed on more than the eight (8) individuals noted previously as placed in ICF-MRs in June 2009.)

Those surveyed who are currently in Alaska are in a variety of placements such as private residences (8), Foster/Therapeutic or Family Habilitation Home (5), Group Home (4), Assisted Living Home/Facility (8), Acute Care Psychiatric Hospital or the Alaska Psychiatric Institute (3), and several other placements such as natural home or apartment, homeless shelter, jail or unknown. The anticipated

length of stay in these placements varied considerably, with 20 estimated as 'More than 2 Years', 19 reported as 'Do Not Know', seven (7) estimated as one-two years, eight (8) estimated as six (6) to 12 months, and the remaining for less than six (6) months.

**Usual Place of Residence**

Survey respondents were asked to select the usual or typical place of residence for the individuals surveyed. The chart that follows illustrates the results of this survey item, which shows that approximately half identified their usual place of residence as either private home/apartment or group boarding home.



**Region of Home/Permanent Residence**

The Regions below were not identified as the home/permanent residence in the survey sample.

| Region             | Description  | Number |
|--------------------|--|--------|
| <b>Region VI</b>   | Aleutian Islands East<br>Aleutian Islands West                           | 0      |
| <b>Region VII</b>  | Bristol Bay Borough<br>Dillingham<br>Kodiak Island<br>Land and Peninsula | 0      |
| <b>Region VIII</b> | Nome Census Area<br>Northwest Arctic                                     | 0      |

The survey indicated the Regions identified below as the permanent home or residence for the identified individuals. Region IV, the Anchorage Municipality was the most frequently noted Region across all age groups in Alaska.

| Region            | Description  | Number | Percent |
|-------------------|--|--------|---------|
| <b>Region I</b>   | Bethel Census Area<br>Wade Hampton   | 1      | 2%      |
| <b>Region II</b>  | Denali Borough<br>Fairbanks North Star Borough<br>Southeast Fairbanks<br>Yukon-Kuskokwim   | 2      | 3%      |
| <b>Region III</b> | North Slope Borough  | 2      | 3%      |
| <b>Region IV</b>  | Anchorage Municipality   | 33     | 55%     |
| <b>Region V</b>   | Kenai Peninsula,<br>Matanuska-Susitna<br>Valdez-Cordova  | 14     | 24%     |
| <b>Region IX</b>  | Haines Borough<br>Ketchikan Gateway Borough<br>Juneau Borough<br>Prince of Wales - Outer Ketchikan<br>Sitka Borough<br>Skagway-Hoonah-Angoon<br>Wrangell-Petersburg<br>Yakutat Borough | 6      | 10%     |
| <b>X</b>          | Other (Out-of-State and Country)   | 2      | 3%      |
| Total             |  | 60     | 100%    |

**Residential Stability**

This survey item assessed 1) the number of times individuals moved in the past year, excluding psychiatric hospitalizations/institutionalization and 2) the number of psychiatric hospitalizations/institutionalizations. The table below shows the averages for these two items based on the 59 survey respondents who answered these items.

| Answer Options  | Response Average |
|---|------------------|
| Number of times moved within the last year - excluding psychiatric hospitalizations/institutionalizations | 1.68             |
| Number of psychiatric hospitalizations/institutionalizations  | 3.63             |

Data for the number of times moved within the last year - excluding psychiatric hospitalizations/institutionalizations indicate an average of 1.68 moves per person. However, the data



also show that 26 respondents reported no moves in the last year and the highest was one with ten (10) moves in the last year.

The number of psychiatric hospitalizations/institutionalizations showed a much higher average of 3.63 with even greater individual variability. Twenty of the responses indicated no psychiatric hospitalizations, one indicated 80, two indicated 20 and from there, the numbers gradually decreased.

Clearly, there are many individuals with relatively stable residential stability, while others have some variability and a few have significant residential instability.

**Intensity of Treatment/Placement Needed**

This survey item addressed the type of treatment/placement needed along with the level of independence and supervision that would be needed to safely address the treatment needs of the individuals surveyed. The table below summarizes the data from this survey item.

| <b>Intensity of Treatment/Placement Needed (one answer only)</b>   |                         |                       |
|--|-------------------------|-----------------------|
| <b>Answer Options</b>  | <b>Response Percent</b> | <b>Response Count</b> |
| Independent; may need home/community-based/outpatient services/therapy.  | 0.0%                    | 0                     |
| Independent; needs home/community-based/outpatient therapy and limited case management.  | 3.3%                    | 2                     |
| Semi-Independent; needs support/supervision and/or moderate case management, home/community-based/outpatient program.                    | 3.3%                    | 2                     |
| Semi-Independent; needs moderate to extensive case management and home/community-based/outpatient program.                               | 5.0%                    | 3                     |
| Needs moderate supervision, extensive case management and home/community-based/outpatient program.                                       | 10.0%                   | 6                     |
| Needs 24 hour MH/DD supervision, home/community-based/outpatient day program and some behavior management (unlocked).                    | 33.3%                   | 20                    |
| Requires 24 hour care with possible locked capacity; total case management, behavior management and extensive therapeutic interventions. | 35.0%                   | 21                    |
| Needs lockable hospital-type setting in facility with seclusion/restraint capacity, diagnostic services and behavior management.         | 10.0%                   | 6                     |
| <b><i>answered question</i></b>  |                         | <b>60</b>             |

78 percent  
47 individuals

Seventy-eight (78) percent of the individuals (47) need 24-hour supervision with varying levels of intensity from home, community-based or outpatient services to a lockable hospital-type facility, all with

the availability of behavior management programming. The remaining 22%, 13 individuals, can be managed in an independent or semi-independent community-based setting with some supervision, case management and possibly therapy or other services. Therefore, a significant majority of the identified individuals need 24-hour intensive, structured active treatment services.

Survey respondents were also asked if residential services were needed. The response below indicates that approximately 72% were in need of a residential facility.

| <b>Does person need a residential facility?</b> |                         |                       |
|---|-------------------------|-----------------------|
| <b>Answer Options</b>                           | <b>Response Percent</b> | <b>Response Count</b> |
| No  | 28.3%                   | 17                    |
| Yes   | 71.7%                   | 43                    |
| <b><i>answered question</i></b>                 |                         | <b>60</b>             |

For the individuals needing a residential facility, the identified facility security indicated that approximately half of the facilities could be open, while the other half should be locked or at least lockable as noted in the following table.

| <b>Facility Type - Security</b> |             |               |                 |                       |
|---------------------------------|-------------|---------------|-----------------|-----------------------|
| <b>Answer Options</b>           | <b>Open</b> | <b>Locked</b> | <b>Lockable</b> | <b>Response Count</b> |
| Facility                        | 22          | 5             | 16              | 43                    |

The next table specifies placement security needs and management considerations for all of the surveyed individuals. The responses with the highest frequency are highlighted in **bold**. For most of the individuals all of these survey items indicated that the security/management issues considerations were a factor two or more times per week, if not daily, except for suicide risk. Sixty percent indicated no suicide risk and another 18% indicated only an occasional risk. There was considerable variance in the risk for walk-away/escape and seclusion or time-out. The walk away/escape risks indicate the need for lockable or locked facilities or other security in order to maintain the safety of the individuals. The seclusion/time-out needs indicate not only the need for seclusion and possibly, even preferably, a comfort or time-out room, but more importantly the need for staff training on low-level behavior management strategies and interventions. Additionally, if seclusion is a permitted intervention, specific training and policies must be enforced to ensure the safety of the individuals requiring these interventions as well as for the safety of the staff.

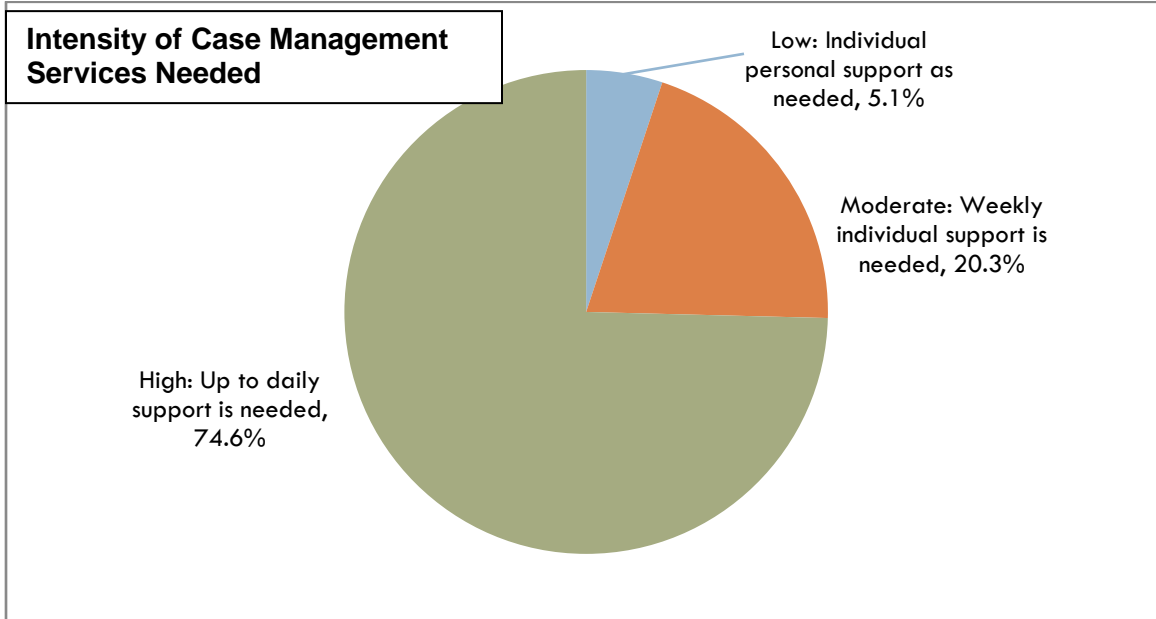
| Placement security/management considerations |           |            |               |           |                |                   |
|--|-----------|------------|---------------|-----------|----------------|-------------------|
| Answer Options                               | None      | Occasional | 1-3/<br>month | Once/week | 2+ /week/daily | Response<br>Count |
| Behavior Management                          | 1         | 4          | 2             | 6         | <b>47</b>      | 60                |
| Close Supervision                            | 1         | 3          | 2             | 3         | <b>50</b>      | 59                |
| Walk away/Escape                             | 6         | 7          | 10            | 9         | <b>28</b>      | 60                |
| Medication Adherence                         | 4         | 5          | 4             | 6         | <b>41</b>      | 60                |
| Suicide Risk                                 | <b>34</b> | 10         | 8             | 2         | 2              | 56                |
| Security                                     | 7         | 9          | 7             | 8         | <b>28</b>      | 59                |
| Seclusion/Time-out                           | 13        | 12         | 3             | 12        | <b>18</b>      | 58                |
| <i>answered question</i>                     |           |            |               |           |                | <b>60</b>         |

### Staffing and Case Management Services Needed

With regard to the staffing needs for residential facilities, only three (3) indicated needing nurses available 24-hours per day, one needing a physician available during the day, while 39 would need non-medical direct care staff around the clock. Clearly the individual staffing needs vary, however as noted in the table below, most of the individuals either do not need nurses or physicians, or having these staff available on-call would be adequate. Some of these medical needs may be addressable through the development of telehealth capacity.

| On site staffing needs for residential facilities: |      |           |     |           |                |
|--|------|-----------|-----|-----------|----------------|
| <b>Staffing Needs - Nurses</b>                     |      |           |     |           |                |
| Answer Options                                     | None | On call   | Day | 24-Hour   | Response Count |
| Facility   | 12   | <b>18</b> | 8   | 3         | 41             |
| <b>Staffing Needs - Physicians</b>                 |      |           |     |           |                |
| Answer Options                                     | None | On call   | Day | 24-Hour   | Response Count |
| Facility   | 12   | <b>28</b> | 1   | 0         | 41             |
| <b>Non-medical Direct Care Staff</b>               |      |           |     |           |                |
| Answer Options                                     | None | On call   | Day | 24-Hour   | Response Count |
| Facility   | 0    | 1         | 3   | <b>39</b> | 43             |
| <i>answered question</i>                           |      |           |     |           | <b>43</b>      |

All of the survey respondents indicated the need for case management services. The estimated intensity of contact for case management services is illustrated in the chart below.



**Disposition Barriers**

The next section of the survey related to potential disposition barriers that might impact placement opportunities. The table below summarizes the responses for this item. Insufficient benefits/resources were the most noted financial barrier however, many respondents identified 'other' or skipped the question, and additional information is not available for these individuals. However, if any of the barriers in this section did not apply, raters were able to skip these items. Raters were also able to indicate more items than one barrier and many of the raters who indicated 'other' also indicated one or more of the other answer options throughout this section.

| <b>Financial (check all that apply)</b> |                         |                       |
|---|-------------------------|-----------------------|
| <b>Answer Options</b>                   | <b>Response Percent</b> | <b>Response Count</b> |
| Insufficient benefits/resources         | 42.0%                   | 21                    |
| Needs to secure employment              | 16.0%                   | 8                     |
| Waiting for receipt of benefits         | 20.0%                   | 10                    |
| Ineligible for benefits                 | 6.0%                    | 3                     |
| Other                                   | 58.0%                   | 29                    |
| <b><i>answered question</i></b>         |                         | <b>50</b>             |
| <b><i>skipped question</i></b>          |                         | <b>10</b>             |

The table below indicates the individuals with barriers related to availability of a suitable placement. It is notable that the needed placement intensity was not available for 30 of the 49 individuals.

| <b>Lack of Suitable Placement (check all that apply)</b> |                         |                       |
|--|-------------------------|-----------------------|
| <b>Answer Options</b>                                    | <b>Response Percent</b> | <b>Response Count</b> |
| Waiting for placement opening                            | 32.7%                   | 16                    |
| Needed (intensity) placement unavailable                 | 61.2%                   | 30                    |
| Medical clearance pending/denied                         | 8.2%                    | 4                     |
| Placement not considered viable                          | 26.5%                   | 13                    |
| Other  | 63.3%                   | 31                    |
| <b><i>answered question</i></b>                          |                         | <b>49</b>             |
| <b><i>skipped question</i></b>                           |                         | <b>11</b>             |

The following table indicates the individuals needing continued treatment and notes if they are waiting for any specific consultation or medical treatment. Most of the individuals (44) need their treatment to continue and many (24) had conditions that are labile or unstable, impacting their placement options.

| <b>Treatment Not Complete (check all that apply)</b> |                         |                       |
|--|-------------------------|-----------------------|
| <b>Answer Options</b>                                | <b>Response Percent</b> | <b>Response Count</b> |
| Waiting diagnostic consultation                      | 3.6%                    | 2                     |
| Waiting medical treatment                            | 3.6%                    | 2                     |
| Treatment in progress                                | 80.0%                   | 44                    |
| Condition is labile/unstable                         | 43.6%                   | 24                    |
| Other  | 32.7%                   | 18                    |
| <b><i>answered question</i></b>                      |                         | <b>55</b>             |
| <b><i>skipped question</i></b>                       |                         | <b>5</b>              |

Challenging/unacceptable behaviors appear to be a significant disposition barrier for many of the individuals, which was expected given the identification of these individuals as at-risk of out-of-state placements for this project. Assaultive/aggressive behavior (51) was closely followed by risk for self-injury (46). Adherence to medications was also noted as a disposition barrier (35) as well as substance abuse problems (18). Behaviors other than the ones noted on the survey were significant (31), however much detail of these was not noted in the comment section other than verbally abusive behaviors.

| <b>Challenging/Unacceptable Behavior (check all that apply)</b> |                         |                       |
|---|-------------------------|-----------------------|
| <b>Answer Options</b>   | <b>Response Percent</b> | <b>Response Count</b> |
| Assaultive/aggressive behavior                                  | 87.9%                   | 51                    |
| Risk for self-injury  | 79.3%                   | 46                    |
| Substance abuse problem   | 31.0%                   | 18                    |
| Unreliable regarding medications                                | 60.3%                   | 35                    |
| Other   | 53.4%                   | 31                    |
| <b><i>answered question</i></b>                                 |                         | <b>58</b>             |
| <b><i>skipped question</i></b>                                  |                         | <b>2</b>              |

The final item in the disposition barrier section was the need for other casework or outpatient services. The majority (37) indicated the need for other services, 20 indicated disagreements about placement needs and 14 were waiting for a case manager to be assigned. Comments related to some of the 'other' responses indicated the need for specialized services for individuals with rare disorders as well as for individuals with traumatic brain injury.

| <b>Other Casework - Outpatient Services Needed (check all that apply)</b> |                         |                       |
|---|-------------------------|-----------------------|
| <b>Answer Options</b>   | <b>Response Percent</b> | <b>Response Count</b> |
| Waiting outpatient appointments   | 13.7%                   | 7                     |
| Waiting case manager  | 27.5%                   | 14                    |
| Other service(s) needed   | 72.5%                   | 37                    |
| Disagreement about placement needs  | 39.2%                   | 20                    |
| Other   | 51.0%                   | 26                    |
| <b><i>answered question</i></b>   |                         | <b>51</b>             |
| <b><i>skipped question</i></b>  |                         | <b>9</b>              |

### Disability and Diagnostic Information

The following section includes information about the specific disabilities of the individuals surveyed as well as their primary and secondary diagnoses. The chart below illustrates the disabilities identified and more than one disability may be reflected for an individual. Forty-seven (47) individuals were identified as having a developmental disability and 47 were also identified as having a psychiatric disability. Although these are not all the same individuals, many were noted as having a co-occurring developmental and psychiatric disability. Nine (9) were identified as having a traumatic brain injury and a few individuals were noted to have other disabilities. Although only one survey was completed on an individual with Dementia/Alzheimer's, meetings with stakeholders indicated that this is a growing population with some complex behavioral needs and some have significant medical issues as well.

| <b>Note all disabilities that apply</b> |                         |                       |
|---|-------------------------|-----------------------|
| <b>Answer Options</b>                   | <b>Response Percent</b> | <b>Response Count</b> |
| Developmental                           | 81.0%                   | 47                    |
| Psychiatric                             | 81.0%                   | 47                    |
| Traumatic Brain Injury                  | 15.5%                   | 9                     |
| Dementia/Alzheimer's                    | 1.7%                    | 1                     |
| Deafness/Severe hearing loss            | 3.4%                    | 2                     |
| Blindness/Severe visual impairment      | 1.7%                    | 1                     |
| Speech impairment                       | 8.6%                    | 5                     |
| Non-Ambulatory/Assisted ambulation      | 5.2%                    | 3                     |
| <b><i>answered question</i></b>         |                         | <b>58</b>             |
| <b><i>skipped question</i></b>          |                         | <b>2</b>              |

Information regarding the primary diagnosis of the individuals surveyed overwhelmingly indicated a Developmental Disorder (62.1%), followed by Schizophrenia (15.5%). The table below shows the other primary diagnoses that were identified. Two (2) survey respondents did not identify a primary diagnosis.

| <b>Primary Diagnostic Category (note only one)</b> |                         |                       |
|--|-------------------------|-----------------------|
| <b>Answer Options</b>                              | <b>Response Percent</b> | <b>Response Count</b> |
| Developmental disorder                             | 62.1%                   | 36                    |
| Child - serious emotional disorder (SED)           | 3.4%                    | 2                     |
| Substance related disorder                         | 1.7%                    | 1                     |
| Schizophrenia                                      | 15.5%                   | 9                     |
| Mood disorder                                      | 5.2%                    | 3                     |
| Anxiety disorder                                   | 0.0%                    | 0                     |
| Dementia/Alzheimer's                               | 0.0%                    | 0                     |
| Other organic disorder                             | 3.4%                    | 2                     |
| Personality disorder                               | 5.2%                    | 3                     |
| Other  | 1.7%                    | 1                     |
| Unknown  | 1.7%                    | 1                     |
| <b><i>answered question</i></b>                    |                         | <b>58</b>             |
| <b><i>skipped question</i></b>                     |                         | <b>2</b>              |

The secondary diagnostic category indicated 13 (22.4%) with a Developmental Disorder, followed by eight (8 - 13.8%) with a Personality Disorder, six with and Organic Disorder other than the one with Dementia/Alzheimer's and five (5 - 8.6%) with either a Substance Related Disorder or Mood Disorder. Thirteen (13 - 22.4%) had diagnoses other than the categories identified on the survey. Some of these included diagnoses of Autism, Fetal Alcohol Spectrum Disorder, Prader-Willie Syndrome, Impulse Control Disorders and Seizure Disorders.

| <b>Secondary Diagnostic Category (note only one)</b> |                         |                       |
|--|-------------------------|-----------------------|
| <b>Answer Options</b>                                | <b>Response Percent</b> | <b>Response Count</b> |
| Developmental disorder                               | 22.4%                   | 13                    |
| Child - serious emotional disorder (SED)             | 5.2%                    | 3                     |
| Substance related disorder                           | 8.6%                    | 5                     |
| Schizophrenia  | 0.0%                    | 0                     |
| Mood disorder  | 8.6%                    | 5                     |
| Anxiety disorder                                     | 1.7%                    | 1                     |
| Dementia/Alzheimer's                                 | 1.7%                    | 1                     |
| Other organic disorder                               | 10.3%                   | 6                     |
| Personality disorder                                 | 13.8%                   | 8                     |
| Other  | 22.4%                   | 13                    |
| Unknown  | 5.2%                    | 3                     |
| <b><i>answered question</i></b>                      |                         | <b>58</b>             |
| <b><i>skipped question</i></b>                       |                         | <b>2</b>              |

Survey respondents also noted that 30 of the individuals were taking psychotropic medications. Although all of these were not indicated this in the answer noted in the table below, the comment section that followed this item did list 35 comments, of which 30 included the list of the specific medications and the other five (5) noted that medication information was not available. For the 30 individuals with a psychotropic medication identified, many of them were taking multiple medications.

| <b>On psychotropic medications?</b> |                         |                       |
|-------------------------------------|-------------------------|-----------------------|
| <b>Answer Options</b>               | <b>Response Percent</b> | <b>Response Count</b> |
| No                                  | 24.1%                   | 14                    |
| Yes                                 | 15.5%                   | 9 (30)                |
| If yes, specify                     | 60.3%                   | 35                    |
| <b><i>answered question</i></b>     |                         | <b>58</b>             |
| <b><i>skipped question</i></b>      |                         | <b>2</b>              |

### Criminal Justice Involvement

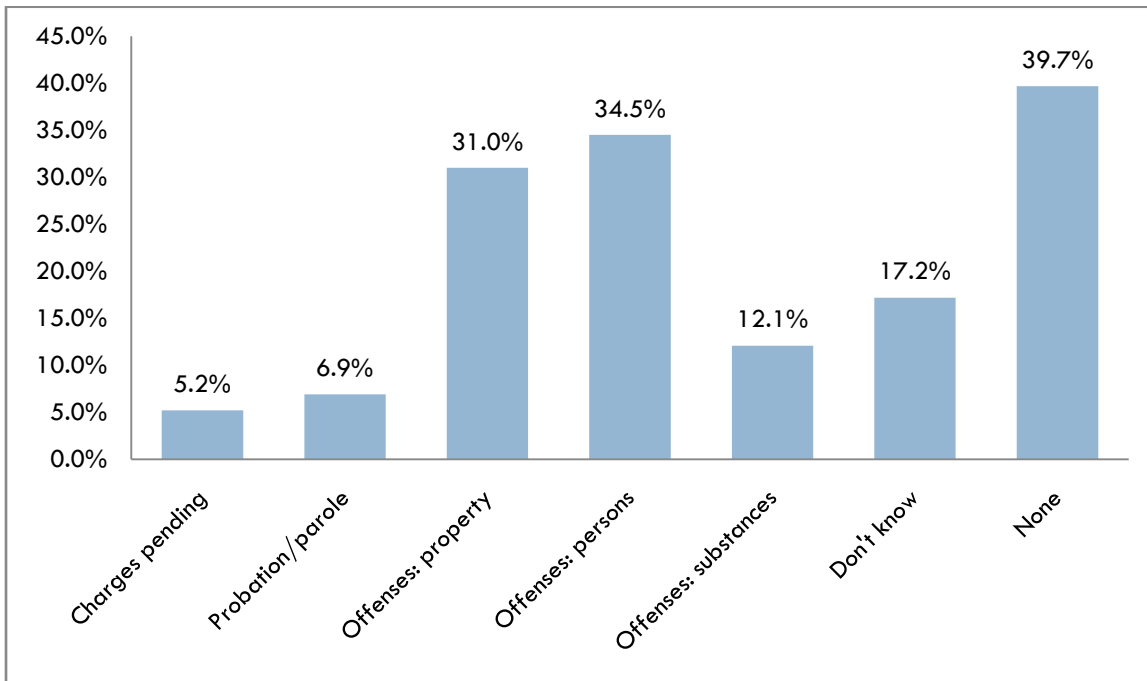
The survey indicated that approximately 33 (57%) of the individuals either did not have criminal justice involvement or the person completing the survey was not aware of any such involvement. The remaining 25 individuals had a combined total of 52 answer options, as noted in the response options below. While most of the offenses against persons were assault-related, several of them were specifically related to sexual assault.



| <b>Note any criminal justice involvement that applies (check all that apply)</b> |                         |                       |
|--|-------------------------|-----------------------|
| <b>Answer Options</b>  | <b>Response Percent</b> | <b>Response Count</b> |
| Charges pending  | 5.2%                    | 3                     |
| Probation/parole   | 6.9%                    | 4                     |
| Offenses: property   | 31.0%                   | 18                    |
| Offenses: persons  | 34.5%                   | 20                    |
| Offenses: substances   | 12.1%                   | 7                     |
| Don't know   | 17.2%                   | 10                    |
| None   | 39.7%                   | 23                    |
| <b><i>answered question</i></b>  |                         | <b>58</b>             |
| <b><i>skipped question</i></b>   |                         | <b>2</b>              |

33  
57%

**Criminal Justice Involvement – Graph of the data above**



### Overall Problem Severity Ratings

This section of the survey requested a rating of either none, slight, moderate or severe for identified problem severity items. The response ratings for each survey item are noted in **bold**. The items with the twenty-five or more 'severe' ratings include: Anxiety, Attention problems, Cognitive/Intellectual/Memory deficits, Resistiveness, Aggressiveness, Antisocial behaviors, Family issues and Interpersonal problems. The two items with the highest ratings of 'none' are Substance abuse (38) and Suicidal/Ideation (30). The item rating the Overall Problem Severity indicates one individual with a 'slight' rating, 19 with a 'moderate' rating and 38 with a 'severe' rating.

| <b>Current Level of Problem Severity Rating</b> |             |               |                 |               |                       |
|---|-------------|---------------|-----------------|---------------|-----------------------|
| <b>Answer Options</b>                           | <b>None</b> | <b>Slight</b> | <b>Moderate</b> | <b>Severe</b> | <b>Response Count</b> |
| Emotional withdrawal                            | 3           | 10            | <b>23</b>       | 20            | 56                    |
| Depression                                      | 8           | <b>21</b>     | 13              | 14            | 56                    |
| Anxiety   | 0           | 8             | 22              | <b>27</b>     | 57                    |
| Hyper affect                                    | 5           | 15            | <b>18</b>       | 17            | 55                    |
| Attention problems                              | 2           | 4             | 21              | <b>30</b>     | 57                    |
| Suicidal/Ideation                               | <b>30</b>   | 15            | 7               | 3             | 55                    |
| Self-injurious behaviors                        | 8           | 13            | 14              | <b>21</b>     | 56                    |
| Thought processes/Psychosis                     | 5           | 11            | 16              | <b>24</b>     | 56                    |
| Cognitive/Intellectual/Memory deficits          | 4           | 3             | 17              | <b>33</b>     | 57                    |
| Self care/Basic needs                           | 2           | 7             | <b>25</b>       | 23            | 57                    |
| Resistiveness                                   | 2           | 4             | 23              | <b>27</b>     | 56                    |
| Aggressiveness                                  | 3           | 10            | 12              | <b>31</b>     | 56                    |
| Antisocial behaviors                            | 4           | 10            | 15              | <b>27</b>     | 56                    |
| Violence/Danger to others                       | 4           | 17            | 12              | <b>24</b>     | 57                    |
| Family issues                                   | 4           | 13            | 13              | <b>27</b>     | 57                    |
| Interpersonal problems                          | 0           | 10            | 20              | <b>27</b>     | 57                    |
| Substance abuse                                 | <b>38</b>   | 8             | 7               | 5             | 58                    |
| Medical condition/Nursing needs                 | 12          | <b>30</b>     | 6               | 8             | 56                    |
| Security management issues                      | 7           | 17            | 9               | <b>22</b>     | 55                    |
| Overall Problem Severity                        | 0           | 1             | 19              | <b>38</b>     | 58                    |
| <i>answered question</i>                        |             |               |                 |               | <b>58</b>             |
| <i>skipped question</i>                         |             |               |                 |               | <b>2</b>              |

### Level of Functioning

The ratings for the current Overall level of functioning indicate that 93% are Low or Very Low. The area related to role performance 'Societal/work/school' had the most (28) 'very low' responses followed by Interpersonal and Cognitive/Intellectual with 22 each. Of the 57 responses for Physical functioning, 56% were rated from 'very high' to 'average', which was the category indicating the highest level of functioning.

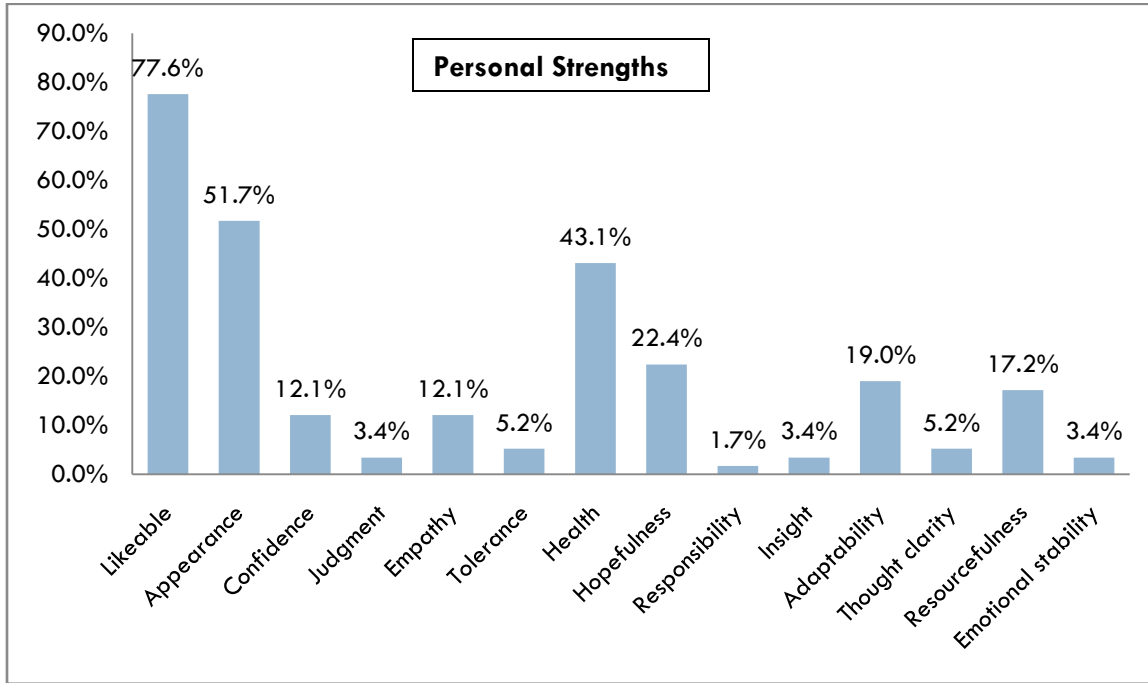
| Current Level of Functioning Rating |           |      |           |           |           |                |
|-------------------------------------|-----------|------|-----------|-----------|-----------|----------------|
| Answer Options                      | Very High | High | Average   | Low       | Very Low  | Response Count |
| Societal/work/school                | 0         | 1    | 6         | 23        | <b>28</b> | 58             |
| Interpersonal                       | 0         | 1    | 2         | <b>32</b> | 22        | 57             |
| Daily living/Personal care          | 1         | 0    | 2         | <b>38</b> | 17        | 58             |
| Physical                            | 1         | 2    | <b>29</b> | 20        | 5         | 57             |
| Cognitive/Intellectual              | 1         | 1    | 4         | <b>29</b> | 22        | 57             |
| Overall level of functioning        | 1         | 1    | 2         | <b>38</b> | 16        | 58             |
| <i>answered question</i>            |           |      |           |           |           | <b>58</b>      |
| <i>skipped question</i>             |           |      |           |           |           | <b>2</b>       |

### Strengths and Resources

In addition to identifying diagnostic and functioning information, it is also important to consider the general and personal strengths of the individuals at-risk for out-of -state placement. Oftentimes, capitalizing on some of the strengths can help off-set the impact of challenging behaviors and functional limitations. The table below shows the responses to this survey item with the most frequent responses highlighted in **bold**. The category with the most responses in the range of 'moderate' to 'very high' was Person - family/friends, indicating some personal supports for 36% of the individuals surveyed.

| General Strengths and Resources Rating |           |      |          |           |           |                |
|--|-----------|------|----------|-----------|-----------|----------------|
| Answer Options                         | Very High | High | Moderate | Some      | Very Low  | Response Count |
| Economic                               | 1         | 1    | 12       | <b>23</b> | 21        | 58             |
| Educational/Vocational                 | 1         | 0    | 9        | 23        | <b>25</b> | 58             |
| Person - family/friends                | 1         | 6    | 14       | 16        | <b>21</b> | 58             |
| Overall Strengths/Resources            | 1         | 0    | 11       | <b>29</b> | 17        | 58             |
| <i>answered question</i>               |           |      |          |           |           | <b>58</b>      |
| <i>skipped question</i>                |           |      |          |           |           | <b>2</b>       |

The ratings for personal strengths indicate the majority of individuals are 'likeable' (77.6%) followed by 'appearance' (51.7%), 'health' (43%), 'hopefulness', 22.4%, 'adaptability'(19%) and 'resourcefulness' (17.2%).



### Survey Summary

The previously presented survey information combined the responses across population age groups, whereas this summary presents the profiles of four population sub-groups broken out by the following age groups: Children up to 13 years of age, Transition age youth 14-25 years, Adults 26 - 55 years and Older Adults 56 years and older. These profiles are intended to guide planning efforts for these population groups, which generally need specific, yet different programs, services and supports.

#### Children:

- Average Age - 11 (range 8-13 years)
- Gender - Male or Female
- Home Region - Anchorage
- Needed Placement - Lockable residential facility with 24/7 supervision and on-call or as-needed nurse and physician
- High level of security, program contact and support needed
- High risk of aggressive, assaultive and, or self-injurious behavior
- Co-occurring developmental and mental health disorder
- Severe overall problem severity and low level of functioning
- Moderate general strengths and resources
- Personal strengths - likeable, good appearance and overall health

#### Transitional Age Youth

- Average Age - 17 (range 14-22 years)
- Gender - 2:1 Male

- Home Region - Anchorage
- Needed Placement - Both unlocked and lockable residential facility with 24/7 supervision and nursing staff daily or on-call and physician on-call
- High level of security, program contact and support needed
- High risk of aggressive, assaultive, self-injurious behavior, and low medication adherence - substance use to a lesser degree
- Co-occurring developmental and mental health disorder, developmental disability only, to a lesser degree
- Severe overall problem severity and low level of functioning
- Some general strengths and resources, less than children
- Personal strengths - likeable, good appearance, overall health and adaptability

#### Adults

- Average Age - 36 (range 26-49 years)
- Gender - 2:1 Male
- Home Region - Anchorage
- Needed Placement - Both unlocked and lockable residential facility with 24/7 supervision and nursing staff and physician on-call (The need for seclusion and/or restraint was noted for several individuals and if this intervention is used, nursing staff should be available 24/7)
- High level of security, program contact and support needed
- High risk of aggressive, assaultive, self-injurious behavior, low medication adherence, and substance use
- Co-occurring developmental and mental health disorder, with several individuals also having a traumatic brain injury
- Severe overall problem severity and low - very low level of functioning
- Low general strengths and resources - these seem to decrease with age
- Personal strengths - likeable, good appearance, overall health and resourcefulness

#### Older Adults

- Average Age – 62 (range 56-71 years)
- Gender – 3:1 Male
- Home Region - Anchorage
- Needed Placement - Unlocked residential and non-residential services with much variability in the staffing needed from weekly to 24/7 supervision and nursing staff and physician on-call for those individuals not placed in a facility
- Moderate level of security, program contact and support needed
- High risk of aggressive, assaultive, self-injurious behavior, and low medication adherence
- Mental health disorder, with possible Alzheimer's or other dementia
- Moderate overall problem severity and low level of functioning
- Low to very low general strengths and resources
- Personal strengths - likeable, and good appearance

Based on data of the individuals included in this survey and given the population distribution in Alaska, developing the more intensive programs and services in the Anchorage area would keep most of the individuals closer to their home community. Then, a 'Center for Excellence' approach could be used to develop and train a resource team to provide direct services in Anchorage, as well as to provide technical assistance and clinical support to the other regions.

It will be important for the resource team to not only have expertise in co-occurring developmental and mental health disorders, but to also have access to persons with expertise in other areas such as substance use disorders, traumatic brain injury, Alzheimer's and other dementias, autism and fetal alcohol spectrum disorder. Availability of clinical subject matter experts in these other areas could begin with contracts either with experts within or outside of Alaska and then overtime, develop broader expertise within the resource team.

## FINDINGS ~ KEY INFORMANT INTERVIEWS

Interviews with key informants identified by the Workgroup occurred from March through June of 2009. Highlights of the comments are sorted by the general themes listed below.

- ◇ ICF-MR History
- ◇ Assessment Process(es)
- ◇ Program and Service Issues and Opportunities
- ◇ Waiver Programs and Issues
- ◇ Transitional Services and Issues
- ◇ Out-of-State Placement Process
- ◇ Workforce Issues
- ◇ Payment and Funding Issues

"We are putting our head in the sand."

Stakeholder comment regarding placing individuals out-of-state for treatment.

### ICF-MR History

Alaska had 160 ICF-MR beds at Harborview plus a few other small programs that were also ICF-MR certified before the closure of Harborview in 1997, in support of de-institutionalization. When the de-institutionalization process began, Alaska initiated contracts with other states and used some small community treatment placements within Alaska. The small residential ICF-MRs in Alaska were eventually de-certified – becoming assisted living homes without oversight from the Centers for Medicare and Medicaid specifically for ICF-MRs or other significant oversight. Most of the current group homes carry a census of three to four, sometimes five individuals.

When Harborview closed, it seemed to be a good plan at the time. Funding was in place for a crisis support and technical assistance team (often referred to as a SWOT team) that assisted with training, case planning and monitoring activities. Changes in administration and priorities eroded this capacity over time, which has limited the State's capacity to serve as the safety net for individuals with serious disorders, especially those who also exhibit complex behaviors. Therefore, many of these individuals are now being treated in ICF-MRs outside of Alaska.

Many advocates resist institution-based services, instead supporting home and community-based services, whenever feasible.

### Assessment Process(es)

Some Level II and III children are placed in Level IV and V facilities, therefore receiving a higher level of services than are clinically indicated, in a more restrictive setting than is needed. (A description of the Level System can be found in Appendix III).

Child head injuries seem to be under-diagnosed. Schools are reluctant to provide testing, which is both a human resource issue and a funding issue. Behavioral problems often trigger testing, which generally results in a mental health diagnosis.

The Inventory for Client and Agency Planning (ICAP) assessment tool is used in Alaska to determine the level of severity and service needs. While this tool is useful, it fails to adequately capture intermittent behaviors. The Support Intensity Scale, used in some states, may be an assessment tool that could more comprehensively address severity and service needs. This tool was developed initially for adults, but there may be a child version under development.

### Program and Service Issues and Opportunities

Alaska currently has numerous three to four bed group homes, congregate apartments, supported living and housing services, as well as some private apartments for individuals with moderate to serious disorders.

Alaska lacks the capacity to adequately serve individuals with co-occurring disorders. Other states are more willing to serve Alaskans with complex behaviors or complex medical needs and the state does not incentivize or pressure local providers to treat these individuals. There are no available substance abuse treatment services for adults who are sex offenders in Alaska. In general, Alaska's providers are 'risk averse', and have not demonstrated the necessary leadership to develop the capacity and competency to serve individuals with the greatest needs.

Strengths-based, individualized, flexible services are needed with a focus on increasing independence and quality of life.

For the mental health population, home and community-based services work the best, not clinic-based services. Serving individuals in their natural environments improves success with managing behaviors.

Alaska lacks housing options for sex offenders and arsonists.

Greater collaboration across state agencies and sharing treatment information would help with continuity of care and improve service efficiency.

Therapeutic Foster Care Homes – Typically serve individuals with behavioral health needs, not developmental disabilities.

Specialty geriopsychiatric services are generally not available in Alaska and this is a growing population of concern. Community mental health centers do not currently provide services to seniors in nursing homes or assisted living facilities such as Pioneer Homes, which is viewed as both a capacity and bureaucratic issue.

Community supports do not exist for older adults with Alzheimer's and mental illness.

Greater nursing home capacity is needed in Alaska. Ideally individuals can be supported longer in their community as they age; however adequate nursing home capacity is needed for some individuals.

Older adults are at-risk of out-of-state placement. A resource center with mental health support consultation would be very beneficial.

The community mental health system 'drops' care when individuals reach the age of 60 years.



Alaska does not have a statewide crisis support line. This would be beneficial to all Alaskans in crisis, family members, as well as to providers.

Crisis assessment and stabilization services are needed, along with short-term step down programs. Ideally this program could have some budget flexibility to provide necessary services without delays.

Individuals with self-injurious and abusive behaviors are the most complex, whereas individuals with inappropriate sexual behaviors have been less of a problem for some providers. Another population that is difficult to treat includes individuals with significant medical needs, especially those who are medically fragile and have ventilators or feeding tubes.

Physical treatment settings are important; whenever possible they should be designed to safely treat the population to be served. (Maine uses some duplexes with one staff for two clients, with the duplex structure allowing the support and back-up of an additional staff.)

More respite services are needed, with adequate reimbursement rates.

The State used to have regional coordinators who collaborated in cross-system problem solving activities regarding treating individuals with complex behavioral management needs. State staff were also more engaged with programs and services. At one time, there was a behavioral SWOT team staffed at the State level, and although it was perceived as valuable, it was intermittent and not sustained.

The State does not technically deny services to individuals; however they are sometimes unable to find the level of services needed.

Quality of care and program oversight have gradually diminished over time for the community-based developmental disability services. The state lacks quality standards and providers do not consistently use operating manuals. Some type of oversight is needed, by the state or a national accrediting body.

Separating the Assisted Living Home licensing from program certification has negatively impacted program quality, especially with staff attrition over time, resulting in the gradual loss of knowledge and experience with both of these important functions.

There is a shortage of appropriate and effective placements for individuals leaving the Department of Corrections, which leads to higher recidivism rates. Many referrals are denied. Others require about six to nine months for the development of a service plan.

### Waiver Programs and Issues

Many of the services for individuals with developmental disabilities are provided through a Home and Community-Based waiver. While adequate care is generally provided, often active treatment is not provided. Additionally, there is minimal oversight of these programs by the State.

The current process for a DD waiver assessment, approval and the start-up of services is lengthy - generally taking one or more months, especially in some parts of the State. Some efforts are currently underway to reduce this with a goal of reducing this to three-five days. Additionally, plans include implementing quality improvement activities to improve data consistency and reporting.

Waiver programs seem to exclude rather than include individuals with the greatest needs by creating boxes that many individuals with complex and co-occurring disorders do not neatly fit.

The waiver programs seem to drive more 'paperwork' and less collaboration. Grants are administered from Juneau and the majority of the providers are in Anchorage. The culture of a partnership with communities and the availability of technical assistance have diminished.

Responding to the different requirements of three divisions within the Department of Health and Social Services regarding waiver requirements, policies, and reporting is very cumbersome. There is lack of coordination and collaboration within this Department. Opportunities for aligning and streamlining should be addressed.

Alaska's waiver programs carve people into boxes and they often do not present with a single issue or diagnosis. The system focuses on the disability and not the person.

### Transitional Services and Issues

Providers have a lack of exposure to the village culture, resulting in treatment approaches that make it very difficult for some individuals to transition back to their village.

The Bring the Kids Home initiative has had a positive impact on staff attitudes and behaviors. There has been much success with this initiative, however Alaska needs to develop and expand program and workforce capacities in order to successfully return all of the children back to the State. Many of the children who remain out-of-state, have complex behavioral needs. Service eligibility and program capacity are different for children and adults. Transitional 'bridge' services are needed for youth as they become young adults.

Children with developmental disabilities are inappropriately being admitted to Residential Psychiatric Treatment Centers (RPTCs), because they do not have a psychiatric disorder, although they may be given a psychiatric diagnosis in order to be admitted. Once placed in an RPTC, many do show improvement from the structured behavioral interventions, although it is very difficult to then transition these children back to the developmental disabilities system due to the lack of continued structure and behavioral supports. Unlike the mental health system, the developmental disabilities system does not have crisis intervention services or residential placements for children, other than foster care placements.

Improved transitional planning and services for individuals being released from the Department of Corrections and the Alaska Psychiatric Institute to communities are needed.

### Out-of-State Placements

Senior and Disabilities Services staff, as part of a Resource Team, engage in out-of-state placement reviews for children. Referrals and requests for ICF-MR placements are coordinated by SDS staff. Generally children receive treatment at API or an acute care hospital when they are presented for these reviews. These staff are also contacted when a child needs to return to Alaska.

Policies and procedures for out-of-state placements (Westcare Management, Inc. – Belmont Home) are currently being developed.

ICF-MR placements in states beside Idaho are being explored because of growing demand.

Out-of-state placements generally involve males more than females and placement last one to six months, or even longer.

Out-of-state placements and institutions should be avoided whenever possible. When individuals are not manageable, sometimes they are sent to jail or to API if they have serious depression or suicidal behaviors.

Infrastructure to transition individuals back to Alaska is critical, yet lacking for individuals placed out-of-state.

### Workforce Issues

Alaskans call the State staff wanting services but an adequate workforce is not available to serve persons with intensive needs within Alaska. Family caregivers and many of the trained staff who provide intensive in-home services experience burnout over time.

“There is no reason for any of these people (individuals with complex behavioral needs) to be in storage”

Alaska stakeholder discussing the need for active treatment.

Alaska does not have sufficient specialty staff such as occupational, physical and speech therapists necessary to provide active treatment and ICF-MR level of care.

The numbers of individuals with diagnoses of Autism Spectrum Disorder and Fetal Alcohol Spectrum Disorder are increasing and Alaska does not currently have adequate experts in these areas.

Hope Community Resources, Inc. provides good community-based services for individuals with developmental disabilities, however competency based, skill enhancement training for staff would be very beneficial.

Much of the direct care workforce consists of individuals with high school diplomas and a personal connection to persons with disabilities. The pay for these individuals is generally not very good and many work two jobs to support themselves and, or their families.

Alaska's University programs are not adequately preparing the undergraduate behavioral health workforce (e.g., social workers and psychologists) and lack graduate level behavioral health programs.

Alaska's University programs do not provide education specific to the treatment of individuals with developmental disabilities. However, there are two courses at the University of Alaska, Anchorage that address positive behavioral supports.

The recent four-year rate freeze has negatively impacted the retention, training and competency of staff working with individuals with disabilities and has resulted in diminishing capacity for some providers to serve more individuals with complex behavioral management needs.

If Alaska was to consider ICF-MR services, workforce capacity and competency would need to be developed. ICF-MR alternatives may be helpful; however, staff competency would still need to be addressed to insure that appropriate treatment services are provided.

State-operated facilities such as Pioneer Homes tend to have less difficulty recruiting a skilled workforce than other facilities; however in some parts of Alaska, state facilities face workforce challenges similar to the other facilities.

The lack of a well-trained workforce may result in misdiagnosis of medical and behavioral symptoms. Issues pertaining to medications, dehydration and lack of care coordination can result in inappropriate interventions.

Injury prevention training is needed for staff and families.

Technical assistance resources are needed for community providers to help direct care staff address complex disorders and challenging behaviors.

Pioneer Homes currently uses Geri-care through Quality Behavioral Solutions - QBS, Inc. and they are very satisfied with this training program. (Appendix V)

### Payment and Funding Issues

There is an established 'Health and Safety' rate to cover the higher costs associated with treating some individuals with special needs, including individuals requiring more intensive services and extra staff. However, the existing approval processes takes an inordinate amount of time.

Office of Rate Review - The rate structure for provider reimbursement varies from provider-to-provider and across systems. Rates are developed by different formulas; some use aggregated cost data, others use historical data, while others use a combination of these. Additionally, providers may further negotiate their individual rates with the State. (Rates were frozen for several years although a four percent increase was funded this year.)

Medicaid funding is not flexible enough to serve individuals with intellectual and developmental disabilities and grant funding cannot be blended with Medicaid funding to provide beneficial services.

Flexible funding to address the needs of individuals identified as 'clinical exceptions' is needed, without a cumbersome process that jeopardizes the safety and well-being of those involved.

When DOC prepares individuals for release back to the community, they experience a very long process (6-9 months) to obtain MRDD waiver funding after the person has been pulled from the waitlist. There is a significant problem convincing agencies to accept clients and without an agency to accept them, the required steps for funding or placement cannot be completed.

Efforts are needed to remove the historical philosophical barriers tied to ICF-MR certification and increase the understanding that ICF-MRs are a financing vehicle, not necessarily an institution.

Home and Community-Based Waiver – supports licensed group homes, non- and for profits - Family Habilitation' - for child assisted living homes.

## FINDINGS ~ FACILITY SITE VISITS

The following facility visits occurred during this Project:

- ◇ Alaska Psychiatric Institute
- ◇ Pioneer Home - Anchorage
- ◇ Pioneer Home - Fairbanks
- ◇ Assets, Inc. - Anchorage
- ◇ Boys and Girls Home – Fairbanks
- ◇ Hope Community Resources, Juneau
- ◇ Belmont Care Center - Pocatello, ID
- ◇ Crestview - Pocatello, ID

### Information from Facility Staff Interviews in Alaska

Hope Community Resources, Inc. had a few small ICF-MRs with eight (8)-12 beds, but these facilities were de-certified.

Agencies such as the Fairbanks Resource Agency provide services to some individuals who would likely receive services in an ICF-MR, if available.

The new Boys and Girls Home in Fairbanks is accredited by the Joint Commission, formerly known as the Joint Commission on Accreditation of Healthcare Organizations (JCAHO). This Residential Psychiatric Treatment Center began serving youth in 2008 and approximately 25% of their campus is in use currently.

The Boys and Girls Home in Fairbanks currently has the physical capacity to serve additional individuals. However, they do not have the staff competency to provide specialized services for individuals with mental health and, or developmental disabilities who present with serious complex behaviors. They may consider leasing to or partnering with an entity with such expertise to provide specialized intensive services within their facility.

There is no specific DD/MH unit at API and there has not been historical support for developing this type of specialty program. Generally, this is seen as contrary to API's acute treatment focus.

Middle-aged and older adults with developmental disabilities and complex behaviors tend to either be placed, 'managed' at the Alaska Psychiatric Institute (API), served by other agencies or end up in a jail.

API offers structured behavior modification and extinction programs to treat some individuals with inappropriate behaviors. (Appendix IV)

API has an average length of stay of about two weeks for the general population. However, there are frequent delays in discharge while some individuals await suitable community placements.

The State does not provide reimbursement for discharge preparation and planning activities when individuals are leaving API.

Pioneer Homes initially functioned more as retirement homes than nursing homes or assisted living facilities. Over time, the age of admissions has crept up as has the level of severity of the population. The Home and Community Based (HCB) Waivers for Older Adults supports services, which allow aging adults to stay in their homes longer. Therefore, when they are no longer able to maintain in the community, they tend to be older and need more intensive services.

Pioneer Homes were initially licensed as nursing homes, however are now licensed under assisted living facility regulations. This allows them to operate with less intensive staffing and services, while also prohibiting them from serving individuals with complex medical and behavioral needs.

Hope Community Resources, Inc. plans to develop the capacity and competency to offer a specialized behavioral management group home. They plan to use a team intervention approach offering early intervention redirection, crisis avoidance and behavior management.

Alaska lacks sufficient long-term care programs and services for seniors. Several years ago, API and Pioneer Homes considered a collaborative venture to serve individuals needing intensive services for extended periods of time. It may be time to re-consider this idea, including the consideration of specialty programs for seniors with Alzheimer's and other dementias who exhibit complex behaviors.

Pioneer Homes, the state-operated assisted living facilities are allegedly unable, due to a license change about five years ago, to treat individuals with a primary diagnosis of serious mental illness. There is lack of clarity regarding whether the scope of individuals who may be served at Pioneer Homes includes person with serious mental illnesses. (A review and possible clarification of the licensing regulation would be helpful.) The current practice, with occasional exceptions, is to deny admissions and services to this population.

Some of the Pioneer Homes provide specific services to individuals with dementia including Alzheimer's. They are able to provide Level I-III services (per billing codes), while nursing homes can take individuals up to a Level V. Populations difficult to serve include older adults with serious mental health disorders and those with significant weight issues. A clarification or change in the license could allow older adults with mental illness to be served, however the rates and staffing would need to be adjusted.

A geriatric-psychiatric unit is needed in the Anchorage area.

All of the Pioneer Homes maintain significant waiting lists, especially for individuals needing Level III services, they highest level they serve. The Anchorage Pioneer Home does have space available on the 4th floor, however significant resources would be needed to bring the space up to the current codes that would be required for occupancy.

### [Information about Two Idaho ICF-MR Facilities Used by Alaska](#)

Westcare Management, Inc. (Belmont Home and Crestview) in Pocatello, Idaho are approved by Alaska as a Medicaid provider. They have an established Medicaid rate, which is not part of the Medicaid 1915(c) waiver program. Alaska has been placing some individuals with complex behavior management needs in these facilities for the past two years. Westcare, Inc. has a corporate office in

Salem, Oregon with programs also in Idaho. Their programs in Idaho include: Belmont Care Center (23 ICF-MR beds in two homes - Pocatello, ID) and Preferred Community Homes (72 ICF-MR beds in 9 homes – Meridan, Nampa and Wendell ID).

Belmont Management operates a variety of care options for individuals living with developmental disabilities including ICF-MR Group Homes, Waiver Apartments, and Mentally Handicapped Sex Offenders Treatment. Their services include but are not limited to self-help, medical, behavioral, vocational, academic, and social. In addition, they have a specialized program for individuals with inappropriate or illegal sexual boundaries. Participants are involved in a caring and safe environment with group and individual treatment settings. The company also provides Waiver services to individuals residing in their own homes or apartments, providing up to 24 hours of supervision and treatment in a community setting. These participants can receive assistance with daily life in the areas of self-help, medical, behavioral, vocational, and social. The staff at Belmont are well trained to meet many different and intense needs for the individuals served. They have the added support from outside professionals with an interest in assisting in the overall treatment plan for each individual. Preferred Community Homes, Inc. also provides services for Individuals with developmental disabilities. They are certified with the Department of Health and Welfare to provide Residential Habilitation Services, along with Behavioral Consultation, Program coordination, transportation and Nursing Services. In addition they also serve individuals with developmental disabilities within their State and federally licensed Intermediate Care Centers.<sup>24</sup>

In June of 2009, Alaska had eight individuals (seven males and one female) placed in unlocked ICF-MR facilities in Idaho, with an additional 13 referrals (persons who have asked for ICF-MH services and have been referred to Westcare (nine males and four females). The largest ICF-MR in Idaho has 15 beds, while most of their other facilities are smaller group homes. These facilities provide highly structured, active treatment seven days per week to individuals ages 18 and older, with most ages 20-30 years. The individuals observed during the facility visit were actively engaged in the program and appeared to function well in these structured, supportive treatment environments.

Westcare, Inc. reports very good working relationships with Senior and Disability Services staff in Alaska and while this partnership has been a good resource for Alaskans needing ICF-MR level of services, Westcare, Inc. believes that it would be much better for the individuals placed and their families if Alaska was able to offer the intensity of needed services in-state.

Admissions from Alaska tend to have a difficult time transitioning to programs in Idaho. One reason involves cultural, geographic and seasonal differences between the two states; such as missing their previous home and families (visits are infrequent if they occur at all, because of the cost), and experiencing day and night transition issues. Another reason is that most individuals coming from Alaska appear unaccustomed to 'active treatment', - the structure and expectations that are part of a more robust individualized treatment program. While individuals in Alaska receive good care, they do not always receive active treatment - instilled with hope and opportunities for some success. Other individuals receive marginal care, as their interventions are focused on confinement and the safety of the individual and others, without behavioral treatment interventions. In some cases following assessment after transfer from Alaska to Idaho, diagnostic changes occur, which may impact the treatment interventions, however generally results in improved outcomes.

## ISSUE ANALYSIS

The creation of a full continuum of care is needed for individuals with a developmental disability, mental illness, Alzheimer's and other dementias, or other cognitive impairments or chronic alcoholics with psychosis, who experience one or a combination of these disorders. Additionally, subsets of this population - persons who are difficult to place and serve within the State of Alaska because of complex behaviors - need dedicated, specialized resources and services. Individuals with complex medical needs also require specialized resources that are not readily available within Alaska, although this population is not the focus of this report.

Alaska chose to close its large institutional ICF-MR facility for the treatment of individuals with developmental disabilities in 1997 (Harborview) in support of less restrictive community-based care. Soon after, the smaller ICF-MRs were also de-certified. Over time, there has been a notable increase in the need to send individuals with complex behaviors out-of-state for treatment. Since the closure of and de-certification of ICF-MRs, there has been a gradual erosion of workforce competency and specialty program capacity to serve individuals with complex, often co-occurring disorders. There has also been a gradual erosion of program oversight and program quality standards and expectations. Oversight from the Centers for Medicare and Medicaid ceased when ICF-MR certification ended and the State has not invested in the workforce capacity to sustain the necessary level of expertise and oversight to promote quality treatment programs and services. Therefore, this population, especially when coupled with complex behaviors, faces limited treatment options within Alaska.

The Alaska Psychiatric Institute and community mental health system have limited resources to serve children with serious emotional disorders and adults with serious mental illnesses. These providers are most challenged by serving individuals with co-occurring disorders, such as developmental disabilities, and mental illnesses. Older adults, especially those with dementia such as Alzheimer's also present treatment and placement challenges, even though their complex behaviors often subside as their disease progresses. Therefore, some individuals with serious mental health and substance use disorders, as well as adults with Alzheimer's and other cognitive impairments are also at-risk of out-of-state placements.

The lack of transitional planning and services across all of the target populations identified in this report is clear. One of the major issues is the provision of services for transitional age youth. Child and adult service eligibility may change, along with service providers, and program expectations. These youth, typically ages 14 -25 experience the same developmental challenges faced by all youth as they mature. However, when confounded with having a serious disability, changes in providers and living situation, and potentially decreased family support, make transition even more difficult. Specific programs and services developed for this population have demonstrated success across the country and offer opportunities for program enhancements for Alaska.

Other transitional challenges were also noted. These included transitions for youth when they leave the juvenile justice system, adults being released from the corrections, adults with serious mental illnesses as they become older adults, as well as transitioning out-of-state individuals back to Alaska. Such transitions are often negatively impacted by the limited continuum of services available in the State.



Alaska clearly does not currently have the intensive program capacity or trained workforce to serve individuals with complex behaviors or other complex needs. This has resulted in growing numbers of individuals being placed out-of-state for treatment. At the same time, there have not been resources dedicated to developing the necessary infrastructure, programs and workforce capacity within the State to begin to address this problem in the future. Many of the providers in Alaska focus on the provision of care versus treatment, and the containment of many individuals instead of structured active treatment with behavioral interventions.

A critical decision point is whether DHSS is willing and able to invest in the development of resources within the State to eliminate, or at least minimize the need for out-of-state placements, or if the preference is to expand the availability of out-of-state placements. Either option has associated costs. Developing a more robust continuum of care for individuals with disabilities and complex behaviors cannot occur immediately, but can begin incrementally as an investment in the treatment of Alaskans in the future. The options that follow are based on the premise that Alaska will elect to enhance existing programs and services and develop additional programs, services, and supports to provide a more robust continuum of care and effectively treat individuals with complex behaviors within the State.

Developing and sustaining the capacity to serve these individuals, both through intensive inpatient and residential services as well as a continuum of community-based services and supports, will increase the opportunities for treatment in the least restrictive setting. This continuum of services also supports the 1999 Supreme Court decision of *Olmstead vs. L.C.* regarding the unnecessary segregation of individuals with disabilities in institutions, which may constitute discrimination based on disability. By developing a continuum of services, individuals in inpatient and residential facilities can be transitioned to community-based services - when they are ready - instead of being contained in a more restrictive environment than is clinically indicated, which can be a legal risk for the State.

## POLICY OPTIONS

The policy options identified below are based on the collective input from numerous stakeholders, the review of several related Alaska reports and plans, findings from the survey sample of individuals at-risk of out-of-state placement due to complex behavioral management needs, as well as information learned from the panel presentation and practices in other states. These policy options are grouped by: 1) Children and Adults, 2) Older Adults, and 3) All Individuals. Implementing the most suitable options will require sustained leadership and an investment in resources and staff time over many years. However, the planning with incremental steps can begin at any time and the sooner an investment in individuals with complex behavioral management needs begins, the sooner the individuals can return or remain closer to their home communities.

### Children and Adults

- Implement a demonstration project, through an RFP process, consisting of three to four small ICF-MRs or other intensive, structured alternatives specializing in the treatment of individuals with complex behavioral challenges. These sites would receive an enhanced rate and specified quality treatment requirements would be monitored and evaluated. The ultimate goal would be to reduce the number of placements to out-of-state ICF-MRs. This would expand the continuum of care within the State and allow for individuals to be treated closer to their home communities. Starting with a demonstration project allows for incremental program development with built-in evaluation components to determine the utility of the treatment services and programs prior to engaging in a system-wide investment. Becoming CMS certified as ICF-MR facilities, as Colorado and other states have done, may enhance Alaska's capacity to draw down federal matching dollars to support the services.
- Implement a demonstration project in which 10-20 individuals with co-occurring disabilities who also exhibit serious complex behaviors are identified for services. Develop a specific funding and resource pool for these individuals either with new dedicated funding or with contributions from existing systems already serving these individuals. Implement individualized, wraparound planning including the development of crisis intervention plans, engaging cross-system expertise. Incentives may be needed to encourage providers to serve this population. This project could be based on the principles of the Assertive Community Treatment (ACT) model, a nationally recognized evidence-based practice for adults with serious and persistent mental illness or an intensive case management model. This approach only focuses on a small number of individuals, but could help address the needs of the individuals with the most complex behavior management needs and may not require additional funding. Another evidenced-based practice that may benefit the youth is Multi-Systemic Therapy, which is; an intensive family- and community-based treatment program designed to make positive changes in social systems

"The system is overburdened and unprepared to deal with difficult cases."

"There is no reason for these individuals to be in storage."

Alaska Stakeholders

(home, school, community, peer relations) that contribute can to the serious disruptive behaviors of children and adolescents who are at risk for out-of-home placement.

- Consider a lease arrangement or partnership with Westcare Management, Inc. to provide acute crisis assessment and stabilization services along with intensive behavior management treatment within Alaska. An enhanced rate would be needed to support necessary staffing levels and competency/training. This option might impact more individuals quicker than the previous two identified options. Also, it brings in outside clinical expertise to support Alaska as internal staff resources and competency are further developed over time.
- Explore reducing the minimum age for admission to group homes to less than 18 years. Many of the individuals identified at-risk of out-of-state placement are transition-age youth 14 - 25 years old. Reducing the admission age for group homes may broaden the continuum of care for this vulnerable population.
- Consider requiring national accreditation, such as through the Commission on Accreditation of Residential Facilities (CARF) or Joint Commission for community-based programs to promote quality standards and quality treatment standards across the State. Although not without cost, this option establishes some consistent quality treatment expectations without requiring significant additional state positions and supports. Another consideration would be to adopt the Centers for Medicare and Medicaid Services Quality Framework as a model when developing and expanding programs.
- Implement a utilization review process for out-of-state placements for adults, similar to the one in place for children. This option could shorten the length of out-of-stay placements and would allow for improved transition back to Alaska, which was a concern identified by numerous stakeholders. Ideally, this option could be implemented quickly and as more resources are developed within Alaska, this process could be shifted to reviewing and coordinating the transfers within the State across the continuum of care, as well as supporting the transitions within Alaska.
- Review the service assessment and approval processes to identify opportunities for increased efficiency and quality. Determine if the ICAP Assessment Tool used by the developmental disability system meets current assessment needs.

“Providers are allowed to cherry-pick the individuals they serve.”

Alaska stakeholder

### Older Adults

- Seek a clarification/interpretation from the State's Attorney General's Office about the ability of Pioneer Homes to admit older adults with serious mental illnesses. Then determine if admitting these individuals is supported by the State/DHHS and whether any regulatory changes would be needed to permit this. It is critical that an adequate continuum of care exist for adults with SMI as they become older. Since Pioneer Homes are state-operated facilities, they are a

reasonable consideration for the provision of services to older adults with SMI. It may be practical, depending on the number of individuals needs such services, that a specialty wing be developed for this population.

- Explore the costs and benefits of reducing the admission age at Pioneer Homes to 55 or 60, instead of the current 65, with special considerations for individuals with serious mental illnesses, Alzheimer's and other dementias and other disabilities.
- Explore the costs and benefits of some or all of the Pioneer Homes becoming licensed as nursing homes instead of assisted living facilities to serve individuals with higher acuity levels. The nursing home level of care provides more robust staffing, including nursing care which is often needed when treating individuals with complex behavioral management needs, especially as they become older and more medical needs arise.
- Pursue a partnership or joint venture between the Anchorage Pioneer Home and the Alaska Psychiatric Institute to serve seniors with mental illnesses and, or developmental disabilities who present with complex behavior management needs. This partnership could provide both inpatient and intensive community-based supports similar to an Assertive Community Treatment Program. (See the Oregon Model.) Staff would also be available to provide consultation and technical assistance to other Pioneer Homes across the State. Shifting to a nursing home license may be necessary.
- Explore the appropriateness of using the Senior Outreach, Assessment and Referral (SOAR) resources to support the partnership/joint effort noted above through the training of community gatekeepers to identify vulnerable seniors and connect with them in non-traditional settings to provide assessment and referral to treatment resources. Community education and outreach, as well as collaboration with primary care providers could enhance behavioral health screening opportunities and identify behavioral health needs before they escalate to critical levels.
- Promote the provision of rehabilitation services to seniors in Pioneer Homes and nursing homes by community mental health clinicians. Such services are not included in the clinic option daily rate and offer the opportunity for a new partnership. Federal matching funds may be available for this service option.
- Explore implementing a Program of All Inclusive Care for the Elderly (PACE) in Alaska. A program such as this could decrease the need for Level I and II beds at Pioneer Homes and increase their capacity to serve individuals with greater Level III-V needs. Therefore, expanding the continuum of care and service capacity whole allowing the State to serve as the 'safety net' for this vulnerable population. Comprehensive, collaborative care management programs for older adults, including those with complex behavior management needs, can be an efficient and effective way to provide quality care and achieve desirable clinical outcomes.

## All Individuals

- Identify subject matter experts from within and outside of Alaska to consult with staff treating individuals with complex behaviors and needs. Developing a Center of Excellence in which a cadre of trained professionals not only provide services to individuals with complex behavior management needs, but also provide technical assistance and consultation services throughout Alaska would be an invaluable resource. These professionals could work together in a 'special facility' or could be a virtual network of identified individuals.
- Assess the feasibility of API offering some training, consultation and technical assistance to community-based providers on behavior modification and extinction techniques to treat some individuals with complex behaviors. Developing a collaborative 'resource' team may be helpful or contract with an entity such as QBS, Inc., as noted below.
- Consider a State-level investment in a program such as the one offered through Quality Behavioral Solutions to Complex Behavioral Problems - QBS, Inc., (based in Holliston, Massachusetts) to provide staff training, technical assistance and care consultation services to fill the existing staff capacity and competency gaps and to build a stronger workforce for the future. Pioneer Homes is already working with this entity, and expanding this relationship could at least in the short-term, provide support to other programs and providers in Alaska.
- Review the reimbursement rates to ensure necessary services are adequately funded. Rates can be effectively used to incentivize the services that are most desired and that produce desirable outcomes.
- Streamline administrative processes to reduce wait times for approvals of special plans, funding, etc. Cumbersome processes are costly and can negatively impact clinical outcomes, while individuals wait for the approval of necessary services and supports.
- Invest in workforce development e.g., training and career opportunities for direct care staff who work with individuals with complex behaviors, building workforce competence and confidence.
- Develop a university program focused on specialty training for Master's level psychologists to meet the needs of individuals with complex, often co-occurring disorders and behavioral management needs. The program would provide education in assessment, behavioral analysis and behavioral interventions and management. This could be offered as a unique Master's or certificate program.

"We are told to provide person-centered services but the State systems are not person-centered. It is a conundrum...how to wrap around services and then bill for the services is an incredible challenge."

Alaska stakeholder

**Appendix I - Key Informant Contacts**

| <b>Name</b>           | <b>Agency</b>   | <b>City</b>   |
|-----------------------|---|---------------|
| Amy Oney              | Assisted Living Association of Alaska                           | Anchorage     |
| Beth Russo            | Alaska Department of Administration- Office of Public Advocacy  | Anchorage     |
| Bill Hogan            | Department of Health and Social Services -Commissioner's Office | Anchorage     |
| Bob Sheehan           | Boys and Girls Home   | Fairbanks     |
| Brenda Knapp          | DHSS- Behavioral Health Treatment and Recovery                  | Juneau        |
| Brenda Mahlatini      | DHSS- Senior & Disabilities Services                            | Anchorage     |
| Colleen Patrick-Riley | Department of Corrections                                       | Anchorage     |
| Courtney King         | DHSS- Division of Juvenile Justice                              | Anchorage     |
| David Cote            | DHSS- Alaska Pioneers Homes                                     | Juneau        |
| David Frain           | DHSS- Anchorage Pioneer Home                                    | Anchorage     |
| Deb Kupfer            | WICHE   | Boulder, CO   |
| Dee Dee Raymond       | Department of Corrections                                       | Anchorage     |
| Denise Daniello       | Alaska Commission on Aging                                      | Juneau        |
| Dennis Mohatt         | WICHE   | Boulder, CO   |
| Dennis Murray         | Alaska State Hospital and Nursing Home Association              | Anchorage     |
| Duane Mayes           | Governor's Council on Disabilities & Special Education          | Anchorage     |
| Emily Ennis           | Alaska Association of Developmental Disabilities Providers      | Fairbanks     |
| Jeff Jessee           | Alaska Mental Health Trust                                      | Anchorage     |
| Jerry Fuller          | DHSS- Commissioner's Office                                     | Anchorage     |
| Jerry Jenkins         | Anchorage Community MH Clinic                                   | Anchorage     |
| Joanne Gibbens        | DHSS- Senior & Disabilities Services                            | Juneau        |
| Karen Ward            | University Center for Human Development                         | Anchorage     |
| Kelly Head            | Westcare Management, Inc (Belmont Home)                         | Pocatello, ID |
| Ken Duff              | Frontier Community Services                                     | Soldotna      |
| Marcy Rein            | DHSS- Senior & Disabilities Services                            | Anchorage     |
| Matt Jones            | Assets, Inc.  | Anchorage     |
| Maureen Harwood       | DHSS- Senior & Disabilities Services                            | Fairbanks     |
| Melissa Stone         | DHSS- Behavioral Health   | Anchorage     |
| Merinda Halladay      | Belmont ICF-MR Administrator                                    | Pocatello, ID |
| Millie Ryan           | Governor's Council on Disabilities & Special Education          | Anchorage     |
| Pam Miller            | DHSS- Behavioral Health Utilization Review Resource Team        | Anchorage     |
| Pat Hefley            | DHSS- Commissioner's Office                                     | Juneau        |
| Rebecca Hilgendorf    | DHSS- Senior & Disabilities Services                            | Anchorage     |
| Richard Nault         | DHSS- Office of Children's Services                             | Juneau        |
| Ron Adler             | DHSS- AK Psychiatric Institute                                  | Anchorage     |
| Stacy Toner           | DHSS- Behavioral Health   | Juneau        |
| Steve Krall           | DHSS- Office of Children's Services                             | Juneau        |
| Steve Williams        | Alaska Mental Health Trust                                      | Anchorage     |
| Steven Young          | Alaska Department of Administration- Office of Public Advocacy  | Anchorage     |
| Teri Firor            | Crossroads Counseling & Training Services                       | Fairbanks     |
| Vickie Wilson         | DHSS- Fairbanks Pioneer Home                                    | Fairbanks     |

**APPENDIX II - Attendees - Complex Behavior Management - Panel Presentation - June 2, 2009**

| <b>Name</b>            | <b>Agency/Organization</b>                                     |
|------------------------|--|
| Adler, Ron             | DHSS- Alaska Psychiatric Institute                             |
| Bishop, Brita          | DHSS- Bring the Kids Home                                      |
| Boggs, Robin           | Crossroads Counseling  |
| Boulette, Kathleen     | SeaView Community Services                                     |
| Bullock, Lesley        | Alaska Commission on Aging                                     |
| Cannon, John           | Mat-Su Services for Children and Adults                        |
| Christopher, Amy       | Ready Care   |
| Churchill, Beverly     | DHSS- Senior & Disabilities Services                           |
| Cote, David            | DHSS- Pioneer Homes  |
| Daniello, Denise       | Alaska Commission on Aging                                     |
| Duff, Ken              | Frontier Community Services                                    |
| Ennis, Emily           | Fairbanks Resource Center                                      |
| Faralan, Rachel        | The ARC  |
| Fitzgerald, Kathy      | Governor's Council   |
| Girod, George          | DHSS- Behavioral Health  |
| Halterman, Anita       | DHSS- Senior & Disabilities Services                           |
| Harwood, Maureen       | DHSS- Senior & Disabilities Services                           |
| Hefley, Patrick        | Commissioner's Office  |
| Hughes, Jonathan       | Alaska Department of Administration- Office of Public Advocacy |
| Jay, Allison           | Department of Corrections                                      |
| Jones, Matt            | Assets, Inc.   |
| Kenney, Lynn           | AADD Coordinator   |
| Lawson, Jimael         | DHSS- Senior & Disabilities Services                           |
| Mayes, Duane           | Governor's Council   |
| Muldoon, Melissa       | Mat-Su Services for Children and Adults                        |
| Oney, Amy              | Mama's Assisted Living Home                                    |
| Patrick-Riley, Colleen | Department of Corrections                                      |
| Raymond, DeeDee        | Department of Corrections                                      |
| Rein, Marcy            | DHSS- Senior & Disabilities Services                           |
| Roth, Greg             | Reach  |
| Russell, Tina          | Connecting Ties  |
| Russo, Elizabeth       | Alaska Department of Administration- Office of Public Advocacy |
| Ryan, Millie           | Governor's Council   |
| Sarka, Joye            | SeaView Community Services                                     |
| Selden, Analisa        | Ready Care   |
| Sullivan, Rita         | DHSS- Behavioral Health  |
| Sumey, Kate            | Department of Corrections                                      |
| Toner, Stacy           | DHSS- Behavioral Health  |
| Tuchkova, Mariya       | DHSS- Senior & Disabilities Services                           |
| Urquhart, Judy         | Blueberry Lodge Group Home                                     |
| VandeCastle, MaryAnn   | Alaska Commission on Aging                                     |
| Walter, Trish          | Mat-Su Services for Children & Adults                          |
| Wellwood, James        | SE Senior Services   |
| Wheeler, Stephanie     | The ARC  |
| Williams, Steve        | Alaska Mental Health Trust                                     |

### Appendix III Residential Level of Care - Overview

| Level and Description   | Staff Levels                                  | Defining Characteristics   | Length of Stay                            |
|---|---|--|---|
| <b>Level I<br/>Day Treatment</b>                                    | 1:6   | An intensive daytime program of structured, supervised, rehabilitative activities for adolescents with behavioral and emotional problems. This category also includes payment for Therapeutic Foster Care  | Daily as needed                           |
| <b>Level II<br/>Emergency Stabilization &amp; Assessment Center</b> | 1:5<br>If under 30 Mo 1:3<br>Awake Night 1:12 | Provides behavioral rehabilitation services (BRS) and temporary residential care for youth who are in immediate danger or need stabilization and assessment of needs services. Services include crisis stabilization, diagnosis, family mediation, individual and group counseling. The emphasis in this setting is on diagnostics and future placement based on therapeutic needs of the child. | Not intended for longer than 30 days      |
| <b>Level III<br/>Residential Treatment</b>                          | 1:5<br>Awake Night 1:12                       | Provides 24-hour BRS and treatment for children/youth with emotional and behavioral disorders. This level is for youth in need of and able to respond to therapeutic intervention, who cannot be treated effectively in a less restrictive environment.  | Up to 18 month / 24 months for SO program |
| <b>Level IV<br/>Residential Diagnostic Treatment</b>                | 1:3<br>Awake Night 1:12                       | Small therapeutic facilities providing structured supervision 24 hours per day in a more restrictive environment. Intensive treatment services include crisis intervention, accurate diagnosis (behavioral, health, mental health, substance abuse, other), behavioral stabilization and management.   | Up to 18 month / 24 months for SO program |
| <b>Level V<br/>Residential Psychiatric Treatment Center</b>         | 1:3   | RPTC programs provide 24-hour interdisciplinary, psychotherapeutic treatment in a "secure" or "semi-secure" facility for children/youth with severe emotional or behavioral disorders and complex, multi faceted diagnoses who have a high risk of harm to self or others.   | As determined by medical necessity        |



## Appendix IV - Behavior Modification Therapy<sup>25</sup>

Behavior modification therapy is based on the concepts of observable antecedents (events that occur before a behavior is apparent), observable behavior, and consequences (the events that occur after the behavior occurs). A behavioral modification program to affect behavioral change consists of a series of stages. An inappropriate behavior is observed, identified, targeted, and stopped. Meanwhile, a new, appropriate behavior must be identified, developed, strengthened, and maintained.

Two types of reinforcers are used to strengthen positive behavior. The use of pleasant rewards to reinforce a positive behavior to help affect change is called **positive reinforcement**. **Negative Reinforcement** strengthens a behavior because a negative condition is stopped or avoided as a consequence of the behavior. Two other reinforcers are identified as those that weaken negative behavior. One is called **extinction**, where a particular behavior is weakened by the consequence of not experiencing a positive condition or stopping a negative condition, and the other is called **punishment**, when a particular behavior is weakened by the consequence of experiencing a negative condition.

In many cases, some form of behavior modification along with cognitive therapy and medication therapy are the preferred methods of treatment for disorders such as ADD, ADHD and Conduct Disorders. Behavior modification and cognitive therapy are also commonly used in the treatment for disorders such as Eating Disorders and Substance Abuse, Mood, and Anxiety Disorders.

## Appendix V - Quality Behavioral Solutions to Complex Behavioral Problems - QBS, Inc.<sup>26</sup>

### **Support for organizations that serve people with behavioral challenges**

Whether your organization is a school, residential program, psychiatric hospital, nursing facility, or a family, QBS has the experience and background to provide you with the support you need.

### **People like those you work with every day**

Whether the people you provide services to are adults, the elderly, children, or adolescents; whether they are affected by psychiatric illness, developmental disability, brain injury, learning disability, or other condition, QBS staff have the experience to help you develop the most effective behavioral interventions to support each person.

### **Challenges like the ones you face**

Whether the behavioral challenges you face come in the form of disruption, physical aggression, self-harm, uncooperativeness, verbal abuse, or other problem behavior, QBS is your solution. We can help you reduce behavioral crises, improve staff competence, and more effectively meet your goals.

Using evidence-based procedures supported by decades of scientific research in the field of applied behavior analysis, we can help you design safe and effective interventions, train you and your staff, track incident patterns, develop new programs, and accomplish the changes necessary to achieve a safe, positive, humane environment in which to work, learn, and grow.

Of the issues facing organizations, behavioral challenges are perhaps the most difficult. Challenging behaviors are not specific to a clinical domain, professional discipline, treatment modality, setting, or stage of recovery. In other words, challenging behaviors can and do occur anytime, anywhere, with anyone. For the individual, this can mean failure to progress, limited residential options, last-resort treatment options (e.g., over-medication, sedation), and possibly injury. For the staff and the organization, individual challenging behaviors can result in property damage, increased costs, regulatory concerns, and injuries. QBS behavioral case consultation will provide your staff with the analysis and treatment recommendations to truly have an impact on the behavioral repertoire and quality of life for the individual and staff alike.

### **Geriatric Friendly Interventions**

The elderly present unique characteristics that often require a specialized approach. Geriatric clients have a susceptibility to many types of injuries, such as fractures, skin tears, and joint injuries. Traditional aggression or crisis management curricula fail to account for these concerns and, as a result, can lead to injury to the individual, instead of ensuring their safety. Significant consideration went into the design, testing, and refinement of each Geri-Care intervention to ensure that the individual is free from harm, while providing care, assisting resistive individuals, avoiding aggression, or releasing from a harmful grab.

Geri-Care™ teaches staff to confidently, safely, humanely, and respectfully enhance the lives of elderly individuals who sometimes exhibit serious challenging behaviors. Staff who participate in a Geri-Care training learn and practice specific, valuable skills designed to help them prevent crises and enhance safety.

### **Case Consultation Features**

- All consultations conducted by credentialed Master's prepared Behavior Analysts with years of experience in a wide array of clinical, training, and management roles
- Experience in virtually every healthcare & educational settings from pre-school to long-term care, with most any behavioral challenge
- Behavioral recommendations consisting of evidence-based procedures supported by up-to-date research
- Several rate structures available depending regularity and contractual arrangement
- QBS Consultation Scorecard™ specifying consultation objectives and deliverables to evaluate delivered services by your QBS Behavioral Consultant
- Promoting a Functional Behavioral Analytic approach to case consults, staff training, program development and management
- Direct or collaborative oversight of Behavioral Rounds - a QBS model for case analysis and behavioral intervention development
- Telephone support available to provide guidance during behavioral conflicts and crises

### **Case Consultation Benefits**

- A training approach to every case consult involving 'on-the-spot', structured coaching, or direct training of behavioral skills.
- Complimentary additional QBS services including behavioral seminars, use of Quality Tracking Solutions™ software, Best Practices Protocols™, Quality Behavioral Competencies™, and other educational and consultation products.

## Appendix VI - Colorado PACE Program<sup>27</sup> - Example

(<http://www.totallongtermcare.org/> May 7, 2009)

**Total Longterm Care** is Colorado's first PACE provider (*Program of All-inclusive Care for the Elderly*). Nationally, PACE is an innovative system of care that provides services in the seniors' homes, including assisted living facilities. Health care and rehabilitation services are provided in the centralized Adult Day/Health Centers.

Serving the Denver, Colorado metro area, Total Longterm Care provides elder care services designed to help senior citizens stay as healthy as possible and in their own homes and communities. Depending on an individual's needs those services may include in-home personal care and chore services, adult day care, medical care, and caregiver support. Total Longterm Care also operates a network of vans to take participants between their homes and the Adult Day/Health Centers.

Total Longterm Care has served the Denver area since 1991.

**Total Solutions** is a technical assistance and management consultant group that specializes in helping organizations evaluate and implement integrated care models such as PACE (Program of All-inclusive Care for the Elderly).

Created by the staff of Total Longterm Care in Denver, Colorado, which operates one of the nation's largest and most successful PACE sites, Total Solutions has more than 15 years experience working with all aspects of the PACE model of care: such as state legislation required to bring PACE to individual states, demographic and economic analyses, strategic planning, program implementation, CMS approval processes, community outreach and marketing, and staff training.

### **Participants must be:**

- Able to live in the community safely as assessed by the PACE care team
- Live in a specific defined service area
- At least age 55
- Meet the state nursing home level of care requirements

***PACE is a model program*** of care for the frail elderly population who are at risk for nursing home placement. By providing a full range of health, social services and in-home assistance to this population, PACE helps elderly individuals age in-place and benefit from the quality, integrated care that defines PACE.

PACE, with its unique capitated funding model saves money in state and federal Medicaid and Medicare expenditures. Most importantly, PACE addresses the growing population of aging with a care model that lets individuals stay in their own homes and communities and maximizes quality of life.

The traditional PACE model uses an adult day/health center as the focal point for providing services. In addition to housing the supportive services an individual requires to maintain health and social function, this day/health center also houses an extensive interdisciplinary team including primary care

physicians, therapists, and nurses. All acute and long-term care services are directly provided by or coordinated through this interdisciplinary team. Because of the capitated payments to the provider, incentives exist for the PACE provider to create a care plan based on the client's existing needs and not based on Medicare and Medicaid fee-for service reimbursement schedules.

CMS and individual states are currently working on approving Rural PACE programs. In these models there is less emphasis on the Day Center model of care and more emphasis on meeting the needs of the rural participant through services provided by existing systems and care programs.

## Endnotes

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<sup>3</sup> HCBS Strategies, Inc. - Recommendations for the Alaska Long Term Care Plan - Final Report, (2008).

<sup>4</sup> Governor's Council on Disabilities and Special Education, 2006-2011 State Plan, pages 9-15.

<sup>5</sup> Hilgendorf, Rebecca; Rein, Marcy; Hamilton, Chris; Division of Senior and Disabilities; Developmental Disabilities Waitlist Report for the Period of July 1, 2007 through June 30, 2008 (December 2008).

<sup>6</sup> Senior and Disabilities Services; Autism Services Report (March 2009).

<sup>7</sup> FASD/RPTC Home and Community Demonstration Project - Modeling, Mentoring and Monitoring: Alaska's focus for youth with dual-diagnoses. (<http://www.hss.state.ak.us/commissioner/fasd-rptc.html> (April 22, 2009).

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<sup>10</sup> Alaska Department of Health and Social Services with the Alaska Mental Health Trust Authority, Moving Forward - Comprehensive Integrated Mental Health Plan: 2006-2011 (September 2006) <http://hss.state.ak.us/dph/healthplanning/movingforward/>.

<sup>11</sup> Alaska Department of Health and Social Services with the Alaska Mental Health Trust Authority, Moving Forward - Comprehensive Integrated Mental Health Plan: 2006-2011 - Update (2008) Pages 75 & 88. (<http://hss.state.ak.us/dph/healthplanning/movingforward> - April 22, 2009).

<sup>12</sup> State of Alaska - Mental Health Block Grant - State Plan for Fiscal Years 2009-2011 - (Excerpt from the Executive Summary).

<sup>13</sup> Alaska's Medicaid Waiver Programs - <http://www.hss.state.ak.us/dsds/waivers.htm> (March 11, 2009).

<sup>14</sup> Hope Community Resources, Inc.; [http://www.hopealaska.org/ah/ah\\_main.cfm](http://www.hopealaska.org/ah/ah_main.cfm) (April 24, 2009).

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<sup>16</sup> Arc of Anchorage -<http://www.arc-anchorage.org/whatwedo.htm> - June 26, 2009

<sup>17</sup> Fairbanks Resource Agency's Annual Report, Framing Our Future (2008).

<sup>18</sup> Alaska Psychiatric Institute - Information provided by Ron Alder (March 17, 2009).

<sup>19</sup> Pioneer Homes - <http://hss.state.ak.us/dalp/details.htm> - March 18, 2009 and updated information from David Cote, Division of Alaska Pioneer Homes Director, April 20, 2009.

<sup>20</sup> Background and Summary of Medicaid Long-Term Care Programs, Residential Services for Persons with Developmental Disabilities: Status and Trends through 2004, pages 83-85.

<sup>21</sup> Bruininks, Robert.; Byun, Soo-Yong; Coucouvanis, K., Lakin, Charlie; Larson, Sheryl; Prouty, Robert W. (2005). Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2004, page 69. Minneapolis: University of Minnesota, College of Education and Human Development. <http://rtc.umn.edu/risp04>.

<sup>22</sup> Centers for Medicare and Medicaid Services, Program for All Inclusive Care for the Elderly (PACE) <http://www.cms.hhs.gov/pace/> (April 24, 2009).

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<sup>24</sup> Westcare Inc. [http://www.westcaremgmt.com/dev\\_disabled.htm](http://www.westcaremgmt.com/dev_disabled.htm) - May 4, 2009

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<sup>26</sup> Quality Behavioral Solutions to Complex Behavioral Problems - QBS, Inc. <http://www.qbscompanies.com/site/> - © 2008 by QBS, Inc. - April 27, 2009.

<sup>27</sup> Colorado PACE Program - <http://www.totallongtermcare.org/> May 7, 2009.