

**OVERVIEW:  
ALASKA  
MENTAL  
HEALTH  
TRUST  
AUTHORITY**

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HEALTH TRUST  
AUTHORITY</SUBJECT><COMM>SHSS29</COMM></TARGET>



## About The Trust

The Alaska Mental Health Trust Authority is a state corporation that administers the Alaska Mental Health Trust, a perpetual trust managed on behalf of Trust beneficiaries. The Trust operates much like a private foundation, using its resources to ensure that Alaska has a comprehensive integrated mental health program to serve Trust beneficiaries. The Trust is overseen by a seven-member board of trustees who are appointed by the Governor and confirmed by the Legislature.

Our goal is to serve as a catalyst for change and improvement in Alaska's mental health continuum of care. To accomplish this, The Trust funds projects and activities that promote long-term system change, including capacity building, demonstration projects, funding partnerships, rural-project technical assistance, and other activities that will improve the lives and circumstances of Trust beneficiaries.

The Trust is the only organization of its kind in Alaska dedicated to assisting those who experience mental illness, developmental disabilities, chronic alcoholism, and Alzheimer's disease and related dementia.

## Vision and Mission

The Alaska Mental Health Trust Authority administers the mental health trust to improve the lives of beneficiaries. Trustees have a fiduciary responsibility to protect and enhance Trust assets in perpetuity for beneficiaries. The Trust provides leadership in advocacy, planning, implementing and funding of a Comprehensive Integrated Mental Health Program and acts as a catalyst for change.

## Trust Beneficiaries

Beneficiaries of The Trust include the following broad groups of individuals:

- People with mental illness
- People with developmental disabilities
- People with chronic alcoholism and other substance related disorders
- People with Alzheimer's disease and related dementia

It is the duty of The Trust to provide leadership in advocacy, planning, implementing and funding of a Comprehensive Integrated Mental Health Program that provides services and programs to better the lives of Trust beneficiaries. The program also may include services for populations broader than The Trust's beneficiary groups without expanding the beneficiary groups. For instance, the program may include prevention or early intervention services for individuals at risk of becoming beneficiaries. The Trust considers prevention of these conditions, where possible, to be part of its mandate.





## Statutory Advisory Boards

**Governor's Council on Disabilities and Special Education**  
**Alaska Mental Health Board**  
**Advisory Board on Alcoholism and Drug Abuse**  
**Alaska Commission on Aging**  
**Alaska Brain Injury Network** (non-statutory) \*

The statutory **Advisory Boards** participate in planning, advising, educating, and making recommendations to public officials related to issues that affect people with disabilities. Board members include people with disabilities, service providers and other community representatives, and make recommendations to the governor and state agencies, Alaska State Legislature, and the Alaska Mental Health Trust Authority.

The Alaska Mental Health Trust Authority (Trust), under the Alaska Department of Revenue, manages the Alaska Mental Health Trust, a state fund dedicated to serving Trust beneficiaries. The Trust receives recommendations from the statutory advisory boards, state and private agencies, the Legislature and the governor, in its planning and expenditure of funds.

### ***Trust beneficiaries include people with:***

- **Developmental Disorders (DD).** *Examples include, Cerebral Palsy (CP), Autism Spectrum Disorders (ASD), Down 's Syndrome, Fetal Alcohol Syndrome (FAS).*
- **Behavioral Health Disorders.** *Examples include, Mental Illness, Substance Use Disorders, Co-Occurring Disorders.*
- **Alzheimer's Disease and Related Dementia (ADRD).** *Examples include, Alzheimer's Disease, Parkinson's Disease, Vascular Dementia, Dementia with Lewy Bodies, Alcohol-Related Dementia, Creutzfeldt-Jakob Disease, Dementia from Head Injury, Frontotemporal Dementia, Normal Pressure Hydrocephalus.*
- **NeuroDisabilities.** *Examples include, Traumatic Brain Injury (TBI), Fetal Alcohol Spectrum Disorders (FASD), Trauma Disorders.*

*\*The Alaska Brain Injury Network (ABIN) is a non-profit organization that participates in the planning and evaluating of Alaska's programs affecting people with brain injuries.*



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## **Trust Beneficiaries with Behavioral Health Disorders**

*Examples include (but are not limited to) Schizophrenia, Mood and Anxiety Disorders, Personality Disorders, Dissociative Disorders, Alcohol-Induced Organic Mental Disorder, Alcoholic Depressive Disorder* <sup>1</sup>

**Mental Illness** is “collectively all diagnosable mental disorders’ or ‘health conditions that are characterized by alterations in thinking, mood, or behavior (or some combination thereof) associated with distress and/or impaired functioning.’ Depression is the most common type of mental illness, affecting more than 26% of the U.S. adult population.”<sup>2</sup> Some examples of mental illnesses include: schizophrenia, bipolar disease, anxiety disorders, depression, personality disorders, mood disorders, eating disorders.

**Substance Use Disorder (SUD)** involves “dependence on or abuse of alcohol or illicit drugs.”<sup>3</sup> The National Center for Biotechnology Information (NCBI) reports that “*Substance Abuse* involves recurrent substance use resulting in a failure to fulfill major role obligations at work, school, or home (e.g. repeated absences or poor work performance related to substance use; substance-related absences, suspensions, or expulsions from school; neglect of children or household); recurrent substance use in situations in which it is physically hazardous (e.g., driving an automobile or operating a machine when impaired by substance use); recurrent substance-related legal problems (e.g., arrests for substance-related disorderly conduct); continued substance use despite having persistent or recurrent social or interpersonal problems caused by or exacerbated by the effects of the substance (e.g. arguments with spouse about consequences of intoxication, physical fights). *Substance Dependence* includes increased tolerance for the substance resulting in the need for greater amounts of the substance to achieve the intended effect; an obsession with securing the substance and with its use; persistence in using the substance in the face of serious physical or mental health problems.”<sup>4</sup>

**Co-Occurring Disorders** are mental health and substance use disorders experienced at the same time. According to the Substance Abuse and Mental Health Services Administration (SAMHSA), approximately 8.9 million adults have co-occurring disorders, 7.4 percent of individuals receive treatment for both conditions, and 55.8 percent receive no treatment at all. SAMHSA also reports: “treatment that addresses mental and substance use conditions at the same time is associated with lower costs and

better outcomes, such as reduced substance use, improved psychiatric symptoms and functioning, decreased hospitalization, increased housing stability, fewer arrests, and improved quality of life.”<sup>5</sup>

***What community supports work for people with Behavioral Health Disorders?***

- *Mental health treatment*
- *Substance abuse treatment*
- *Intensive case management*
- *Counseling and/or therapy*
- *Respite for families*
- *Ongoing support services*
- *Employment support*
- *Housing assistance*

**For information about behavioral health disorders, contact the  
Alaska Mental Health Board: <http://dhss.alaska.gov/amhb/Pages/default.aspx>  
Advisory Board on Alcoholism and Drug Abuse:  
<http://dhss.alaska.gov/abada/Pages/default.aspx>  
and Alaska Mental Health Trust Authority: [www.mhtrust.org](http://www.mhtrust.org)**

<sup>1</sup> *Alaska Statute related to Trust beneficiaries with mental illness and/or substance use disorders: [AS 47.30.056\(d\)](#) and [AS 47.30.056\(f\)](#).*

<sup>2</sup> *Center for Disease Control (CDC): [www.cdc.gov/mentalhealth/basics.htm](http://www.cdc.gov/mentalhealth/basics.htm)*

<sup>3</sup> *Substance Abuse Mental Health Services Administration (SAMHSA): [www.samhsa.gov](http://www.samhsa.gov)*

<sup>4</sup> *National Center for Biotechnology Information (NCBI): [www.ncbi.nlm.nih.gov](http://www.ncbi.nlm.nih.gov)*

<sup>5</sup> *Substance Abuse Mental Health Services Administration (SAMHSA): [www.samhsa.gov](http://www.samhsa.gov)*



#### Statutory Advisory Boards:

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## Trust Beneficiaries with NeuroDisabilities

*Examples include (but are not limited to) Traumatic and Acquired Brain Injury (T/ABI), Fetal Alcohol Spectrum Disorders (FASD), Post Traumatic Stress Disorder (PTSD) <sup>1</sup>*

Neurodisabilities are caused from structural damage to the brain – from trauma, disease, degeneration, or toxic substances – resulting in functional impairment of memory, attention, executive and cognitive functioning, decision-making, impulse control, emotional regulation, pain and pleasure management, add/or sensory processing. Neurodisabilities can be traumatic, acquired, or congenital. They can include Traumatic or Acquired Brain Injury (T/ABI), Fetal Alcohol Spectrum Disorders (FASDs), Post-Traumatic Stress Disorder (PTSD).

**Brain Injury** is damage to the brain resulting in impairments in physical, cognitive, speech/language, and/or behavioral functioning. Damage may be caused by an external physical force, insufficient blood supply, toxic substance, malignancy, disease-producing organisms, congenital disorders, birth trauma, or degenerative processes. Both Traumatic Brain Injury (TBI) and Acquired Brain Injury (ABI) are examples of brain injury.

- **Traumatic brain injury (TBI)** is caused by a bump, blow, or jolt to the head, or a penetrating head injury that disrupts normal brain function. The severity of a TBI may range from “mild,” (brief change in mental status or consciousness) to “severe” (an extended period of unconsciousness or amnesia). According to the Alaska Trauma Registry, there have been nearly 15,000 Alaskans with TBI requiring hospitalization from 1991-2011. <sup>2</sup> The most recent five-year average is approximately 680 Alaskans per year. <sup>3</sup> Emergency room visits are about 1,250 per year, with only the largest hospitals reporting. <sup>4</sup> Examples of TBI include Concussion, Shaken Baby Syndrome.
- **Acquired Brain Injury (ABI)** is caused by the shearing of brain nerve fiber due to trauma or by cell death related to swelling, bleeding, disease, or loss of oxygen to the brain. Whether mild, moderate, or severe, acquired brain injury can cause cognitive, speech/language, physical, and/or behavioral dysfunction. The Alaska Department of Health and Social Services (DHSS) hospital discharge data reports more than 1,000 cases of acquired (non-traumatic) brain injury annually. <sup>5</sup> Examples include Parkinson's Disease, Anoxic Event, Vascular Dementia.

**Fetal Alcohol Spectrum Disorders (FASDs)** “are a group of conditions that can occur in a person whose mother drank alcohol during pregnancy. These effects can include physical problems, and problems with behavior and learning. Often, a person with an FASD has a mix of these problems. The term FASD is not meant for use as a clinical diagnosis, but rather to refer to the range of effects that can happen to a person whose mother drank alcohol during

pregnancy. These conditions can affect each person in different ways, and can range from mild to severe.”<sup>6</sup> Some FASDs include:

- **Fetal Alcohol Syndrome (FAS)** is the most severe on the FASD spectrum and includes: abnormal facial features, growth deficiencies, central nervous system damage, causing difficulties with learning, memory, attention, impulsivity, communication, and judgment.
- **Alcohol-Related Neurodevelopmental Disorder (ARND)** includes cognitive, behavioral, emotional, and adaptive functioning deficits. Common problems include memory, attention, judgment, math, and poor impulse control.<sup>7</sup>
- **Alcohol-Related Birth Defects (ARBD)** includes physical deficits that include problems with heart, kidneys, bones, and hearing.<sup>3</sup>

**Post Traumatic Stress Disorder (PTSD)** is the development of characteristic symptoms following exposure to one or more traumatic events. Symptoms can present as fear-based re-experiencing with emotional and behavioral expressions, mood and negative thinking, reactive externalizing, and dissociative symptoms. According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), PTSD can result from exposure to exposure to war, threatened or actual physical assault, threatened or actual sexual violence, being kidnapped, torture, severe motor accidents, etc. Individuals with PTSD may be quick-tempered, engage in aggressive verbal or physical behavior without provocation, reckless or self-destructive behavior, concentration and memory difficulties, sleep difficulties, heightened sensitivity to potential threats, excessive alcohol or drug use, and/or suicidal behavior.<sup>8</sup>

### **What community supports work for people with neurodisabilities?**

- *Case management*
- *Job coaching, mentorship*
- *Safe, affordable housing*
- *Rehabilitation services*
- *Life skills training*
- *Peer support/mentoring*
- *Training for professionals*
- *Respite for caregiver*

**For information about neurodisabilities, contact  
the Alaska Brain Injury Network [www.alaskabraininjury.net](http://www.alaskabraininjury.net),  
the Alaska FASD Partnership <http://dhss.alaska.gov/abada/Pages/fasd.aspx>,  
and Alaska Mental Health Trust Authority [www.mhtrust.org](http://www.mhtrust.org)**

<sup>1</sup> Alaska Statute related to Trust beneficiaries with neurodisabilities [AS 47.30.056\(e\)\(5\)&\(7\)](#).

<sup>2</sup> Ambrosia Bowlus, MPH, MLS(ASCP), Public Health Specialist II, Department of Health and Social Services, Division of Public Health, Section of Emergency Programs, email February 19, 2013.

<sup>3</sup> Hillary Strayer, Senior Specialist, Injury Prevention Program, Alaska Native Tribal Health Consortium, Division of Community Health Services, Alaska Trauma Registry Study, 2010.

<sup>4</sup> Alice Rarig, MA MPH PhD, Planner IV, Department of Health and Social Services, Division of Public Health, Emergency Department data), email March 21, 2013 (largest hospitals only, does not include six tribal hospitals or military hospitals).

<sup>5</sup> Sharilyn Mumaw, Department of Health and Social Services, Division of Senior and Disabilities Services, Traumatic/Acquired Brain Injury Program, November 2012.

<sup>6</sup> SAMHSA FASD Center for Excellence, [www.fascenter.samhsa.gov](http://www.fascenter.samhsa.gov).

<sup>7</sup> The term fetal alcohol effects (FAE) was previously used to describe intellectual disabilities and problems with behavior and learning in a person whose mother drank alcohol during pregnancy. In 1996, the Institute of Medicine (IOM) replaced FAE with ARND and ARBD.

<sup>8</sup> *Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-V)*. Published by American Psychiatric Association, Washington D.C., 2013.



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## **Trust Beneficiaries with Developmental Disabilities**

*Examples include (but are not limited to) Intellectual Disability, Cerebral Palsy, Autism, Down's Syndrome <sup>1</sup>*

**Developmental Disability (DD)** is "a severe, chronic disability that is attributable to a mental and/or physical impairment that 1) is manifested before the individual attains age twenty-two; 2) is likely to continue indefinitely; 3) 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."

Individuals with disabilities, such as intellectual disability, cerebral palsy, autism, Down syndrome, mental illness, brain injuries, and fetal alcohol syndrome, may be considered to have a developmental disability if they meet the above conditions.

### ***What community supports work for people with Developmental Disabilities?***

- *Supported employment*
- *Day habilitation*
- *Respite care*
- *Community inclusion supports*
- *Residential supported living*
- *Nursing oversight*
- *Care coordination*

**For information about developmental disabilities, contact the Governor's Council on Disabilities and Special Education: <http://dhss.alaska.gov/gcdse/Pages/default.aspx> and Alaska Mental Health Trust Authority: [www.mhtrust.org](http://www.mhtrust.org)**

<sup>1</sup> *Alaska Statute related to Trust beneficiaries with developmental disabilities: [AS 47.30.056\(e\)](#)*

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## **Trust Beneficiaries with Alzheimer's Disease and Related Dementia (ADRD)**

*Examples include (but are not limited to) Alzheimer's Disease, Parkinson's Disease, Vascular Dementia, Dementia with Lewy Bodies, Alcohol-Related Dementia, Creutzfeldt-Jakob Disease, Dementia from Head Injury, Frontotemporal Dementia, Normal Pressure Hydrocephalus <sup>1</sup>*

**Alzheimer's Disease** is "a progressive, degenerative disorder that attacks the brain's nerve cells, or neurons, resulting in loss of memory, thinking and language skills, and behavioral changes. These neurons, which produce the brain chemical, or neurotransmitter *acetylcholine* break connections with other nerve cells and ultimately die. For example, short-term memory fails when Alzheimer's disease first destroys nerve cells in the hippocampus, and language skills and judgment decline when neurons die in the cerebral cortex." <sup>2</sup>

**Dementia** is "a general term that describes a group of symptoms – such as loss of memory, judgment, language, complex motor skills, and other intellectual function – caused by the permanent damage or death of the brain's nerve cells, or neurons. Alzheimer's Disease is the most common cause of dementia in persons over the age of 65, and represents about 60% of all dementias." <sup>2</sup> Examples of dementia include: Parkinson's disease (caused by degeneration of the nerve cells that produce dopamine), vascular dementia (caused by stroke or blockage of blood supply), alcohol-related dementia (caused by sustained use of alcohol), trauma dementia (caused by head injury).

"The clinical symptoms and progression of dementia vary, depending on the type of disease causing it, and the location and number of damaged brain cells. Some types progress slowly over the years, while others may result in sudden loss of intellectual functioning. Each type of dementia is characterized by different pathologic, or structural, changes in the brain – such as accumulation of abnormal plaques and tangles in individuals with Alzheimer's disease, and abnormal tau protein in individuals with frontotemporal dementia." <sup>3</sup>

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According to the Alaska Commission on Aging (ACOA), there are approximately 5,400 Alaskans age 65+ living with Alzheimer's disease. This number does not include those

with “related dementias” or persons with early onset. The number of Alaskans with ADRD is believed to be higher than 5,400. According to Medicare claims data, there are 4,147 older Alaskans age 65+ (2012) diagnosed with Alzheimer's disease receiving health care services paid for by Medicare. In the U.S., there are over 5 million with ADRD (2010) that will more than triple (16 million) by 2050. (Source: *Journal of Neurology* 2013). Nearly one in three seniors who die each year has Alzheimer's disease or another form of dementia.<sup>4</sup>

### ***What community supports work for people with ADRD?***

- *Improved public awareness and understanding about Alzheimer's disease and related dementia*
- *Care coordination and case management to develop personalized plans of care*
- *Adult Day Programs including those that specialize in providing care for persons in various stages of the disease*
- *Caregiver training, counseling, and support groups*
- *Respite for caregivers*
- *Early and thorough diagnostic evaluation and accurate diagnosis. Each type of dementia requires its own differential care*
- *Education, counseling, and support groups for persons with Alzheimer's disease and related dementia, especially for those newly diagnosed*
- *Transportation*
- *Senior meals*
- *Home modification to improve accessibility and prevent falls*
- *One-stop for information and referral services*
- *Assisted living facilities specializing in dementia care*
- *Competent and caring professional and family caregivers*
- *Improved safety for persons with dementia who may wander unattended*
- *Safe and appropriate housing for seniors with dementia and challenging behaviors*

**For information about ADRD, contact the Alaska Commission on Aging:**

<http://dhss.alaska.gov/acoa/Pages/default.aspx>

**and Alaska Mental Health Trust Authority: [www.mhtrust.org](http://www.mhtrust.org)**

<sup>1</sup> Alaska Statute related to Trust beneficiaries with ADRD: [AS 47.30.056\(a\)](#)

<sup>2</sup> Alzheimer's Foundation of America, [www.alzfdn.org/AboutAlzheimers/definition.html](http://www.alzfdn.org/AboutAlzheimers/definition.html)

<sup>3</sup> Alzheimer's Foundation of America, [www.alzfdn.org/AboutDementia/definition.html](http://www.alzfdn.org/AboutDementia/definition.html)

<sup>4</sup> Alaska Commission on Aging <http://dhss.alaska.gov/acoa/Pages/default.aspx>



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## Community Support Services for Alaskans with Disabilities

- Community-based support services help people with mental and physical disabilities, and their families, live meaningful and productive, crisis-free lives.
- Community support services include assisted living, case management, housing assistance, job coaching and supervised mentorship, education and training, peer support, transportation services, respite and counseling for families.
- Community support services help people remain stable, with a better chance of staying employed, housed, and contributing productively in the community.
- Community support services 'level the playing field' – giving people with disabilities supports that help them live normal lives.
- Community support services are less expensive than institutional care – costing half to one-fourth less than nursing home care<sup>1</sup> and half to one-fifth less than a psychiatric hospital.<sup>2</sup>
- There will always be costs associated with serving vulnerable Alaskans – either on the front-end with community support services, or on the back-end with emergency rooms, psychiatric hospitals, nursing homes, and jail. It's less expensive to serve people at home and in the community than in institutionalized care.
- Community support services support local economies by providing work for psychologists and medical professionals, personal care attendants, case managers, respite workers, and treatment providers – all of whom contribute to the healthy workforce and strong economy.

- Community support services for people with **developmental disabilities** (Down's syndrome, autism), might include life skills assistance, service animal, drop-in day center, job coaching.
- Community support services for people with behavioral health disorders, such as **mental illness** (schizophrenia, bipolar disorder) or **substance use disorders**, might include a supported group home with on-site case management, job mentorship, treatment, peer support, counseling for families.
- Community support services for seniors with **Alzheimer's Disease** or **related dementia** might mean assistance with chores and meals, respite for family caregivers, adult day programs, personal care assistance, care coordination/case management, home-delivered meals.
- Community support services for people with **neurodisabilities** (traumatic brain injury, fetal alcohol spectrum disorders, complex trauma disorders) might include ongoing case management, job coaching/mentorship, life skills training, supported housing, respite for caregivers.

### ***Consequences of reduced funding for community support services:***

- *People without supports will be more likely to become unstable and move into institutional care.*
- *People transitioning from the corrections, juvenile justice, foster care, therapeutic court programs, etc. who do not get support services – such as housing, employment, peer support, transportation, vocational rehabilitation, etc. – are more likely to recidivate and return to incarceration.*
- *More professional service providers will be out of work.*
- *The state will pay more in the end for more costly institutional services in corrections, juvenile justice, psychiatric hospitals and nursing homes.*

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<sup>1</sup> Comparing home and community-based services like personal care attendants (average 2010 annual cost \$23,387/person) and Medicaid waiver services (average 2010 annual cost ranging from \$23,299 to \$43,662/person) to skilled nursing facility costs (average 2010 annual cost \$91,988/person). **Source:** Long-Term Forecast for Medicaid Enrollment and Spending, Supplements 2008, 2009, and 2010, Department of Health and Social Services; Division of Senior and Disability Services waiver data.

<sup>2</sup> Comparing outpatient mental health services (average 2010 annual cost of \$8,712/person) to inpatient psychiatric treatment (average 2010 annual cost of \$21,674/person) and residential psychiatric/behavioral rehabilitation services (average 2010 annual cost of \$48,766/person). **Source:** Long-Term Forecast for Medicaid Enrollment and Spending, Supplements 2008, 2009, and 2010, Department of Health and Social Services.



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## Complex Behavior Collaborative

- The Complex Behavior Collaborative (CBC) provides consultation and training in specialized behavior management for caregivers and community providers who serve people with disabilities with challenging behaviors—such as aggression, inappropriate sexual behaviors, wandering, self-harm, aggression, etc.
- People with disabilities are at higher risk for experiencing complex and difficult-to-manage behaviors.
- Caregivers and providers who are not equipped with specialized skills often struggle because they cannot handle those in their care with challenging behaviors.
- Many caregivers and service providers report they lack adequate skills to serve their clients with complex behaviors.
- When caregivers develop behavior management skills, the individuals they serve are more likely to stay stable, avoid crisis, and stay out of more costly institutional care—such as Alaska Psychiatric Institute (API), residential treatment, nursing homes, or jail.
- The Collaborative serves mental health providers, home care providers, classroom teachers, rural behavioral health aides, nursing home staff, etc.
- The Collaborative serves people with serious mental illness (SMI), intellectual or developmental disability (I/DD), traumatic brain injury (TBI), Alzheimer's disease and related dementia (ARD), fetal alcohol spectrum disorders (FASD), substance use disorders, and trauma disorders.
- In FY12, funding was allocated to set up the Collaborative and develop the provider agreements. In FY13 and FY14, the Collaborative opened and has been expanding both its client and consultant base. In FY15, we are seeking annualized funding to ensure that the consultation and training services of the Complex Behavior Collaborative continue to be available for caregivers and providers, and the individuals they serve.