



**BEHAVIORAL HEALTH DEPARTMENT – PRIMARY CARE CENTER AND FIREWEED
TREATMENT GUIDELINES FOR
AUTISM, PDD & MR**

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 TREATMENT PLAN FOR AUTISM, PDD AND MENTAL RETARDATION..... 18

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Executive Summary

Introduction and statement of Intent

This treatment guideline is intended to assist clinicians in the Behavioral Health department in treatment planning and service delivery for patients with Autism, Mental Retardation and Pervasive Developmental Disorder (PDD). It may also assist clinicians treating patients who have some of the signs and symptoms of Autism, PDD and Mental Retardation but who do not meet the full criteria for these diagnoses. The treatment guideline is not intended to cover every aspect of clinical practice, but to focus specifically on the treatment models and modalities that clinicians in our outpatient treatment setting could provide. These guidelines were developed through a process of literature review and discussion amongst clinicians in the Behavioral Health department and represent a consensus recommendation for service provision for these disorders within our clinic. The guideline is intended to inform both clinical and administrative practices with the explicit goals of outlining treatment that is, effective, efficient, culturally relevant, acceptable to clinicians, program managers, and patients

Definitions of disorders

Autism is a complex developmental disorder involving impairment in a number of areas. Central features of the disorder include significant impairment in social interaction; absent, delayed or idiosyncratic communication; and restricted or repetitive behaviors and interests. Clients with this disorder often, though not always, have significant cognitive disabilities (mental retardation). These delays or deficits must be present before the age of 3. It is the relative lack of social interest and development that separates this from other developmental disorders.

Asperger's Disorder is often called "high functioning autism" and includes qualitative impairment in social interaction (failure to develop peer relationships or lack of social or emotional reciprocity), restricted or stereotyped motor behavior, and persistent preoccupation with very narrow or unusual interests. There is no language delay or cognitive deficit.

Mental Retardation refers to significant limitations in general intellectual functioning and concurrent significant limitations in adaptive functioning as determined by culturally fair standardized assessment. These limitations must be present before the age of 18 years. The degree of mental retardation is classified as follows:

- | | |
|--------------------------|---|
| * Mild – IQ of 55-70 | Adaptive behavior deficits in two or more domains |
| * Moderate – IQ of 35-54 | Adaptive behavior deficits in two or more domains |
| * Severe – IQ of 20-34 | Adaptive behavior deficits in all domains |
| * Profound – IQ below 20 | Adaptive behavior deficits in all domains |

Pervasive Developmental Disorder Not Otherwise Specified is the term used when there is a severe and pervasive impairment in the development of reciprocal social interaction or verbal and nonverbal communication skills, or when stereotyped behavior interests and activities are present, but the criteria are not met for a specific developmental disorder. This category includes atypical autism and those where a significant delay is present but concern exists that it may be due to major environmental or medical factors that have not yet been identified. This category is also appropriate for individuals whose presentation needs to be monitored for a period of time before a more definitive diagnosis is made.

General Goals of treatment

Treatment is aimed at:

- Improving core deficits in communication, social skills and social interest
- Optimizing function in behavior, academic performance, developmental milestones
- Reducing disruptive behaviors
- Lowering caregiver burnout
- Encouraging development of problem solving skills

This guideline is designed for general use for most patients but may need to be adapted to meet the special needs of a specific patient as determined by the patient's provider.



Summary of 1st, 2nd and 3rd line treatment

There are several model programs for the treatment of autism and mental retardation that have demonstrated effectiveness though none of them eliminate or cure the disorders. There is even less evidence for specific treatment of other pervasive developmental disorders. However, all model programs have several features in common. Interventions for clients with Autism, PDD and MR require highly structured, intensive, long-term behavioral programming and communication skill development. Model programs with demonstrated efficacy include:

- More than 20 hours per week of programming specific to developing skills in communication, reducing sensory reactivity and developing adaptive functioning skills.
- 3 years or more of intensive services
- Lifelong supportive services including extensive parent/caregiver training in behavioral modification
- Therapists/clinicians with specialized training and supervised clinical experience with this disorder
- A multidisciplinary treatment team with occupational therapy, speech therapy, psychology and case coordination

Our clinic lacks the resources or mandate to provide primary treatment of Autism, Mental Retardation and Pervasive Developmental Disorders. However, patients and families may benefit from some of our programming such as:

- Social skills group
- Parenting classes
- Family Therapy
- Medication management
- Family Health Resource assistance applying for Social Security Disability Income
- Support Groups for parents of children with special needs
- Specialized diagnostic assessment and referral

Clinical and demographic issues that influence treatment planning

To benefit from the skills and therapy groups we have, a patient would need to be relatively high functioning and have a developmental age similar to other patients in the group (age 5 up). Parents with children of any age or functional level may benefit from supportive services. Aggression towards self or others, or other behavior disruptive to the treatment of other patients in the clinic may disqualify some patients with these disorders from participation in services.

Because of the lack of intensive, coordinated services to address pervasive developmental disorders in our community, treatment planning may be based largely on availability of resource rather than demonstrated effectiveness of treatment. Families may also benefit from assistance in identifying and becoming eligible for appropriate school-based resources as most intervention services for clients under the age of 22 are available to varying degrees through the educational system.

Assessment

The Diagnostic Testing team will be reviewing and commenting on the Psychological Testing column for every disorder.

	Psychiatric Assessment	Psychological Testing	Screening/Scales
Indications	<ul style="list-style-type: none"> Unmanageable behavior or other symptoms that have not improved with standard interventions Patient is already on psychotropic medication and symptoms remain problematic. Patient or guardian requests a second opinion or wishes to consider pharmacologic intervention 	<ul style="list-style-type: none"> Diagnostic clarification or symptoms not improved with standard interventions or psychotropic medication. Question only answerable by psychological testing Appropriate medical assessment completed by primary care provider. 	<ul style="list-style-type: none"> Establish baseline and/or monitor treatment effectiveness Identify frequency of symptoms
Contraindications	<ul style="list-style-type: none"> Collateral information not available (e.g. caregiver/ significant other, appropriate records) Consent not available (if patient has guardian) Patient or guardian has forensic rather than therapeutic goal (i.e. compliance with court or parole requirements, disability determination, etc.) 	<ul style="list-style-type: none"> Extremely dangerous to self and/or others Untreated psychosis Initial evaluation / assessment is not done Referral question not answerable and/or not clear Alternate organic causes of the disorder have not been ruled out School or other source has already conducted psychological testing within the last year 	<ul style="list-style-type: none"> Limited English proficiency. Attention span inadequate Lack of cooperation
Structure	In patients with cognitive impairment who cannot give adequate history, parent or guardian with knowledge of the patient's history must be available for assessment.	Depends on the referral question	To be reviewed by Testing Team.

Specialized psychological assessment needs to be completed to make a diagnosis for these mental health issues. This assessment should occur **before** a clinician begins therapy with a client suspected of having autism, mental retardation or a pervasive developmental disorder. This type of psychological assessment is outside of the scope and practice of a master's level clinician and is not something usually done by a psychiatrist unless he or she has training in the administration of standardized psychological assessments.

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Assessment (continued)

The following steps would permit the clinician to obtain the needed information:

1. If the client is birth to three years of age, refer to the Program for Infants and Children (PIC) at 561-8060 for an evaluation. PIC also provides in-home speech, occupational and physical therapy services for their clients, so the referral should be made as soon as possible.
2. If the client is three to five years of age, refer them to the Mt. Iliamna School Child Check program at 753-8235 for an evaluation. This Anchorage School District program does assessments and offers specialized interventions (speech, occupational therapy, behavioral, etc.) for children identified with an Early Childhood Developmental Delay.
3. If the child is school aged and has never been assessed or received any services, refer to their neighborhood school for an initial evaluation of cognitive functioning, speech, adaptive behavior and emotional regulation. Note: It is extremely unusual for someone with one of these disorders to have bypassed an assessment at school.
4. **ALSO**, please refer undiagnosed clients that you suspect of having autism, mental retardation or a pervasive developmental disorder to their primary care provider. A complete medical work-up will need to be done to rule out a health or medical reason for the presentation.

Once the assessment information is reviewed, the clinician can determine if the client is appropriate for a group. Family therapy that emphasizes behavior management skills could be occurring during the

Modalities & Treatment Models

Group Therapy

We offer no primary treatment for Autism, PDD or MR. However, patients with these disorders could participate in groups as adjunctive treatment.

INDICATIONS	CONTRAINDICATIONS	RELATIVE CONTRAINDICATIONS
<ul style="list-style-type: none"> ▪ Customer is 6 years old or older ▪ Mild severity ▪ Able to tolerate affect without behavior destructive to group ▪ Sufficient verbal and/or cognitive ability to benefit from treatment ▪ For customers under 18 years old, parental education and involvement is predictive of good outcome and should be integrated whenever possible. 	<ul style="list-style-type: none"> ▪ Dangerousness to self or others ▪ Lack of commitment from customer and if customer not competent, lack of commitment from parent and/or legal guardian ▪ Sexually acting out behaviors ▪ Court ordered treatment with insufficient participation from child and/or guardian ▪ Child abuse investigation incomplete ▪ Severe untreated hyperactivity ▪ Untreated Psychosis or mania ▪ History of chronic or extreme disruptive behavior in groups ▪ Acute intoxication or withdrawal from alcohol or other substances 	<ul style="list-style-type: none"> • Relatives or significant others in the same group (unless it is a family group and/or couples group) • Meets CMI or SED criteria without receiving rehab services • Untreated substance dependence

STRUCTURE

- Groups will be facilitated by a Master's Level Therapist and Case Manager
- For 17 years old and below, developmental age grouping recommended (base this on developmental age and not just chronological age).
- For 18 years old and above consider adult services

Duration	60 to 90 minutes. May be brief or long-term depending on treatment goals or treatment progress.
Frequency	Once a week
Size	<ul style="list-style-type: none"> ▪ 6 to 9 years old 2-3 customers per provider ▪ 10 years old and over 4-6 customers per provider Note: Groups are not functional when they contain more than 4-6 children or adolescents with developmental disabilities.
Open vs. Closed	Open or Closed with windows

TREATMENT MODEL

Primarily behavioral.

This guideline is designed for general use for most patients but may need to be adapted to meet the special needs of a specific patient as determined by the patient's provider.



Individual Therapy

Individual Therapy for patients with Autism, MR or PDD is unlikely to be effective at altering behavior or improving function and is not an efficient use of our resources. Empirical evidence suggests it is not efficacious. Therapeutic interventions should be addressed towards caregiver support and training. See page 8.

Family Therapy / Couples Therapy

Adjunctive therapy offered for parental caregiver support/education. Family or caregiver education and involvement is predictive of good outcome and should be integrated whenever possible. Caregivers can benefit even if the client is unable to participate.

INDICATIONS	CONTRAINDICATIONS	RELATIVE CONTRAINDICATIONS
<ul style="list-style-type: none"> ▪ Adjunctive treatment for any age. ▪ First line of treatment for 0 to 5 year old ▪ Disorder is impacting the family and/or relationship ▪ Family dynamic exacerbating or triggering symptoms ▪ Caregiver has sufficient verbal and/or cognitive ability to benefit from treatment 	<ul style="list-style-type: none"> ▪ Lack of commitment from parent and/or legal guardian ▪ Court ordered treatment with insufficient participation from guardian or caregiver ▪ Untreated Psychosis ▪ Acute intoxication or withdrawal from alcohol or other substances 	<ul style="list-style-type: none"> ▪ Custody dispute ▪ Child abuse investigation incomplete ▪ Current Domestic violence or abuse of child ▪ Active substance abuse or dependence in caregiver

STRUCTURE

Duration	60 minutes
Frequency	<ul style="list-style-type: none"> ▪ Weekly or Twice a Month ▪ Up to 8 sessions for treatment

TREATMENT MODEL

Behavioral, psychoeducation, skills building, and supportive/expressive models.

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Individual Medication Management

There is no specific medication to treat the core deficits of Autism, MR & PDD. Behavioral and mood symptoms are frequently targeted with second generation anti-psychotics, mood stabilizers, and anti-depressants. The evidence base is too thin to justify a specific algorithm for management of mood or behavior disturbance in these patients. Our primary care providers have noted a very poor response to stratera in individuals with prenatal exposure to drugs or alcohol.

INDICATIONS	CONTRAINDICATIONS	RELATIVE CONTRAINDICATIONS
<ul style="list-style-type: none"> ▪ Legal guardian consent ▪ Current biopsychosocial intake or psychiatric assessment is available. ▪ Recommended concurrent with psycho-education and behavior management skills training. 	<ul style="list-style-type: none"> ▪ Refuses Medication Management ▪ Acute intoxication or withdrawal from alcohol or other substances 	<ul style="list-style-type: none"> ▪ Disorder is caused by an untreated physiological disorder. ▪ Client lacks caregiver with sufficient cognitive skill to appropriately administer medications.

STRUCTURE

Duration	30 minutes
Frequency	Monthly

TREATMENT MODEL

Medication management is adjunctive to other behaviorally oriented interventions.

Group Medication Management

Need for parent and/or guardian presence makes group medication management impractical for customers 0 to 18 years old. The group may also be impractical for customers with mental retardation or significant auditory information processing deficits.

INDICATIONS	CONTRAINDICATIONS	RELATIVE CONTRAINDICATIONS
<ul style="list-style-type: none"> ▪ If symptoms stable and patient cannot return to primary care for maintenance treatment, group medication management should be considered. ▪ History of non-compliance ▪ Able to tolerate affect without behavior destructive to group ▪ Frequently misses scheduled appointments 	<ul style="list-style-type: none"> ▪ Significant cognitive or language deficits. ▪ Acute dangerousness to self or others ▪ Untreated psychosis ▪ Sexually acting out behaviors ▪ Severe untreated hyperactivity 	<ul style="list-style-type: none"> • Relatives or significant others in the same group (unless it is a family group and/or couples group) • Meets CMI or SED criteria without receiving rehab services • No child care available

STRUCTURE

Duration	▪ Indefinite
Frequency	As indicated by clinical stability.
Size	4 to 6 patients per provider
Facilitators	One psychiatrist or ANP, and one Registered Nurse or Case Manager
Open vs. Closed	Open

TREATMENT MODEL

Medication management is adjunctive to other behaviorally oriented interventions.

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Psycho Educational Groups

This modality can be extremely helpful for families of patients with autism, mental retardation or other pervasive developmental disorders. Psycho education should be considered for the family even if the customer cannot participate.

INDICATIONS	CONTRAINDICATIONS	RELATIVE CONTRAINDICATIONS
<ul style="list-style-type: none"> ▪ Sufficient verbal and/or cognitive ability to benefit from treatment ▪ Able to tolerate affect without behavior destructive to group ▪ Could benefit from skills development 	<ul style="list-style-type: none"> ▪ Dangerousness to self or others ▪ Sexually acting out behaviors ▪ Untreated Psychosis or mania ▪ History of chronic or extreme disruptive behavior in groups ▪ Untreated substance dependence ▪ Severe untreated hyperactivity 	

STRUCTURE

Groups will be facilitated by 1 to 2 Case Managers who have experience working with clients who have developmental disabilities.

Duration	60 to 90 minutes for up to 8 weeks
Frequency	Once a week
Open vs. Closed	Open

TREATMENT MODEL

Psycho-educational and experiential with opportunity for client-focused problem-solving.

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Case Management

Patients with these disorders require intensive case management, including in-home and in-school services. We do not provide these services. Our case management should assist families of clients with Autism, Mental Retardation or Pervasive Developmental Disorders to access community-based, wrap-around services. Behavioral Health case management support would be adjunctive to the case management services provided in the primary care setting.

All Ages	
Record Review	<ul style="list-style-type: none"> ▪ Clarify reason for requesting services. ▪ Collect collateral history and/or past treatment records (especially IEP and previous school testing) ▪ Obtain patient and/or guardian consent ▪ Liaison with outside agencies and/or link to community resources ▪ Lead orientation to services ▪ Review and/or conduct client initial screening and triage
Treatment	<ul style="list-style-type: none"> ▪ Psychosocial education ▪ Maintain supportive contact ▪ Triage current clients in crisis ▪ Crisis management (e.g. triage, risk assessment, skills coaching, referrals when needed) ▪ Community liaison work and coordination of care ▪ Manage charts ▪ Provide aspects of treatment ▪ Assist with group preparation ▪ Draft treatment plans ▪ Follow-up when customer fails to keep appointments. ▪ Encourage medication and treatment compliance
Follow-up	<ul style="list-style-type: none"> ▪ Liaison with outside agencies ▪ Link to community resources ▪ Gather and disseminate information from external referral sources

Referral

INDICATIONS

- All patients with Autism, MR or PDD should be referred to additional community resources. Please refer to the community resources list below.
- Meets CMI criteria and not receiving rehab services
- Needed treatment is available elsewhere.

COMMUNITY RESOURCES

Cognitive Disorders (Alzheimer's, dementia, TBI)

Alzheimer's Agency Resource Agency of Alaska (907-561-3313) www.alz.alaska.org

As Alaska's resource on Alzheimer's disease, the Alzheimer's Disease Resource Agency of Alaska (ADRAA) is committed to providing information, education and services for individuals with Alzheimer's disease and related disorders (ADRD) and their caregivers. We have served Alaskans since 1984, and today we help more than 5,000 people annually. As a non-profit statewide organization, we provide care coordination, respite and education programs to family caregivers and health care professionals. We are your resource for information and can refer you to services in Alaska or the contiguous U.S.. Our offices are located in Anchorage, Palmer, Juneau and Fairbanks. Call 561-3313 in Anchorage or 1-800-478-1080 for more information.

Day Break Adult Day Center (907-346-2234)

Day supervision; group and individual socialization; music, culture, pet therapy; health, medication, and exercise activities; noon meal; family education and support.

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Salvation Army Older Alaskans Program (907-349-0613)

Congregate meal sites, home delivered meals, transportation and shopping, home chore services, adult day care, some employment.

Access Alaska (907-248-4777)

www.accessalaska.org

Information and referral, counseling and service coordination, housing and assistance, personal assistant referral, transportation, support groups, rehabilitation services.

Support Groups

- Access Alaska- groups for stroke survivors, mobility, family-caregiver, head injury. Call for days/times (907-248-4777)
- Alzheimer's Resource Agency of Alaska offers support for care givers of persons with Alzheimer's disease and related disorders: General Care Giver Group, 10 a.m.-noon, first Thursday; Adult Child/Relative Care Giver Group, 10:30 a.m.-noon, second Thursday; Spousal Care Giver Group, 10:30 a.m.-noon, third Thursday. All groups meet at 1750 Abbott Road. In January, an Eagle River support group will begin meeting 12:30-2 p.m. the third Monday of the month at Community Covenant Church, 16123 Artillery Road (Linda, 696-5497). Support groups meet statewide, call 561-3313 for dates, times and locations. (www.alzalaska.org)
- Caregiver Connection, a program of Salvation Army Serendipity Adult Day Services, links families caring for a loved one at home with community resources. (279-0501)
- Caregiver Support Group for those caring for seniors with Alzheimer's disease or other dementias, meets 10:30 a.m.-noon the second and fourth Tuesday of each month at the Eagle River VFW, across from the fire station. (Susan Smiley, 696-0736 or dksmileys@gci.net; or Liz Hunt at the Alzheimer's Association, 561-3313)
- Traumatic Brain Injury Parent & Student Groups: First Wednesday of the month, Brain Injury Association Building, 1251 Muldoon Road, 7-8:30 pm (333-5634)

Autism/PDD

Alaska Autism Resource Center (AARC) (907-562-7372)

www.sesa.org/aarc/

This program was created to facilitate services that will enable Autism Spectrum Disorders (ASD) to become widely recognized and well supported throughout the state of Alaska. AARC also facilitates systems change that will enable the community of Alaskans affected by ASD, their families, and service providers to become a coherent, collaborative, and self-organized community.

Alaska Youth and Family Network (907-770-4979)

www.ayfn.org

Alaska Youth and Family Network advocates for families and children with social/emotional/behavioral challenges and related disabilities to be included as equal partners with professionals in developing policies, programs and ensuring adequate services and information.

ARC of Anchorage (907-277-6677)

www.arc-anchorage.org

Services for children and adults with developmental disabilities. Individually designed programs. Supportive services, resource center, community living, respite care and family support, wrap around case management, vocational/pre-vocational programs.

Catholic Social Services - Special Needs Services (907-276-5590)

http://electra.he.net/~csalaska/special_needs.php

Special Needs Services provides care for children who experience developmental disabilities and offers a support system for their families. Trained providers accompany clients on outings and care for them from their homes.

FOCUS, Inc. (907-688-0282)

www.focusoutreach.org

FOCUS, the Family Outreach Center for Understanding Special Needs provides family centered early intervention/infant learning services for infants and toddlers from birth to three years of age who experience a delay or a disability in Eagle River/Chugiak and through a satellite site in Cordova. FOCUS provides a range

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BHS Treatment Guidelines for **Autism, PDD & MR**

of supports for individuals who experience developmental disabilities and their families including: residential and day habilitation, chore services and hourly and daily respite care. The agency also offers short term assistance and referral (STAR) for families, respite, support in accessing core services and a summer program.

Parents Inc. (907-337-7678)

www.parentsinc.org

Parents Inc. is a parent training organization based on the philosophy that parents of all children with disabilities can help other families face similar challenges.

Programs for Infants and Children, Inc. (907-561-8060)

www.picak.org

Programs for Infants and Children, Inc. provides early intervention services for infants and toddlers with special needs. Training is individualized and implemented in a family centered home environment. Multi-disciplinary team includes early intervention specialists, speech, physical, and occupational therapists.

Stone Soup Group (907-561-3701)

www.stonesoupgroup.org

Care coordination, information and referral, family support, resource center.

Special Education Service Agency (907-562-7372)

www.sesa.org

The Special Education Service Agency (SESA) is a publicly funded agency which provides assistance to Alaskan school districts and early intervention programs serving students with low incidence disabilities.

Support Groups

- Parents In Transition: Connect with other parents of youths with disabilities for information about resources, agencies and topics relative to transition, 7-9 p.m. first Thursday, King Career Center, 2650 E. Northern Lights Blvd. (742-3874)
- Asperger Parent Group: Fourth Thursday of the month, College Gate Elementary, Room 32, 7-9 pm (333-5634)
- Autism Parent Group: First Tuesday of the month, College Gate Elementary, Room 32, 7-9 pm (333-5634)
- Caregivers of Children with Disabilities Discussion Group: First Monday of the month, 2550 Denali Street, Suite 1606, 6-7 pm, (907-334-9842)

Primary Care

Children with autism, mental retardation and other forms of PDD are more likely than other children to experience problems with speech and language, with the digestive system, with low motor tone and with sensory-motor integration. A high percentage of these clients also have vision and hearing deficits. The primary care provider needs to be actively involved in their treatment to ensure that emotional or behavioral dysregulation or a decline in functional ability does not have an organic basis.

The behavioral problems of children with these disorders are unlikely to be well managed by a primary care medical team alone.

INDICATIONS for management solely in the primary care clinic setting

- Refuses specialty mental health care
- Specialty Mental Health care not available
- Uncomplicated Medication Management
- Maintenance Medication Management

CONTRAINDICATIONS for management solely in the primary care setting:

Higher intensity services needed to ensure safety to patient or others

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Appendix A: Glossary

Term or Acronym	Term Definition
Acute Intoxication	A reversible substance-specific syndrome due to recent ingestion of (or exposure to) a substance. Clinically significant maladaptive behavior or psychological changes that are due to the effect of the substance on the central nervous system and develop during or shortly after use of the substance. (Adapted from DSM-IV)
Acute Withdrawal	A substance-specific syndrome due to the cessation of (or reduction in) substance use that has been heavy and prolonged. (Adapted from DSM-IV)
CBT	Cognitive Behavioral Therapy
Closed Group	Customers may enter only at initial formation of group.
Closed Group with Windows	Customer enrollment available intermittently
Eclipse	Overshadow, for example, when the symptoms and dysfunction related to one disorder overshadow another making treatment of one more pressing.
Exposure Therapy	Exposure therapy (Haug et al, 2003) with or without response inhibition is most cited as effective for specific phobia, obsessive compulsive disorder and PTSD. Generally, these run 10 -12 sessions with each session targeting a specific skill, exposure level and cognitive reframing. Manuals are available to guide clinical work.
Intervention	Any thoughtful action taken by a clinician or customer with the purpose of addressing a perceived problem or therapeutic goal
IPT	Interpersonal Therapy
NOS	Not Otherwise Specified
Open Group	Participants can enter at any time.
PDD	Pervasive Developmental Disorder
Play Therapy	Play therapy is a form of psychotherapy for children who have been traumatized. It encourages children to explore their emotions and conflicts through play, rather than verbal expression.
Psychiatric Assessment	Formal assessment by a psychiatrist or ANP
Psychoeducation	teaching and training about the disease or problem for which the customer or family member is seeking treatment. Psychoeducation is frequently presumed to be part of all forms of assessment and treatment, yet additional interventions that emphasize education about an illness are often shown to improve outcomes over treatment as usual. Psychoeducation can be incorporated into many treatments, but can be viewed as an intervention in its own right and can be delivered by non-professional staff such as case managers or health educators.
Psychological Testing	Formal psychological assessment which includes clinical interview and appropriate tests conducted by a psychologist and/or psychometrician. This testing is standardized and normed.
Screening/Scales	Brief, easily administered screening and scales which do not require advance training to interpret.
Social Rhythm Therapy	A structured psychotherapy combining elements of behavioral therapy and psychoeducation and shown to reduce rates of relapse and rehospitalization in bipolar disorder

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Term or Acronym	Term Definition
Structural Family Therapy (SFT)	Structural Family Therapy is model of treatment in which a family is viewed as a system with interdependent parts. In this treatment model, the family system is understood in terms of the repetitive patterns of interaction between the parts. From such a perspective, the goal of structural family therapy is to identify maladaptive or ineffective patterns of interactions, then alter them to improve functioning of the subparts and the whole.
TBI	Traumatic Brain Injury
Treatment Modality	For purposes of this guideline, we have defined “modality” as the structure in which the customer receives treatment, for example, individual psychotherapy, group psychotherapy, or psychoeducation.
Treatment Model	For purposes of this guideline, we have defined the “model” of care as the underlying theoretical approach to clinical intervention, for example, Cognitive Behavioral Therapy, Insight Oriented Therapy, Interpersonal Therapy.
Untreated Psychosis	For the purposes of this treatment guideline, we define untreated psychosis as psychotic symptoms that are prominent, disruptive in some way, and for which the customer is not accepting or engaging in care that would mitigate such symptoms. The diagnosis of a psychotic disorder or the presence of psychotic symptoms at some point in the course of illness or treatment should not be a barrier to participation in treatment that might be helpful. However, nor should a customer with a significant psychotic disorder be treated with some forms of psychotherapy from which they are not likely to benefit. Clinical judgment will be needed in selecting appropriate treatment for each customer.
Untreated Substance Dependence	Because “dual diagnosis” is the norm, rather than the exception in behavioral health settings, customers with substance abuse problems should not be excluded, a priori, from participation in treatment for other mental health conditions. However, the impact of their substance use on their capacity to participate in treatment must be assessed on an ongoing basis. Customers with current substance dependence may not be appropriate candidates for some forms of treatment.

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Appendix B: Literature Summary

**Evidence Based Clinical Guidelines
Southcentral Foundation Research Project
Summary Sheet
Autistic Spectrum Disorders and Pervasive Developmental Disorder**

Diagnosis: This category targets three diagnostic entities first appearing in infancy, childhood or early adolescence. They are as follows:

299.00 Autistic Disorder: This disorder requires symptoms from three broad categories: 1) Impaired Social Interaction (lack of peer relationship, impaired use of non-verbal language) 2) Communication Impairments (delayed development of spoken language, poor conversation skills, lack of make believe play) and 3) Repetitive Behaviors (preoccupation is parts of objects, repetitive motor mannerisms, very limited pattern of interest)

299.80 Asperger's Disorder: This disorders requires symptoms in two broad categories similar to Autism. 1) Social Interaction Impairment (lack of age appropriate peer relationships, lack of shared enjoyment or interest with others, impairment in non-verbal language) and 2) Restricted and Limited patterns of interests, behaviors and activities (very routinized life, restricted pattern of interest, stereotyped or repetitive behavioral mannerisms). There is usually no cognitive delay in their development.

299.80 Pervasive Developmental Disorder NOS (Including Atypical Autism): This disorder is used when there is severe and pervasive impairment in reciprocal social interaction with or without verbal and nonverbal communication skill OR when the restricted and limited behavioral and interest pattern doesn't meet the above other two diagnoses.

General Information: This review searched the following data bases: Cochrane Reviews, American Psychological Association, American Psychiatric Association, The Journal of Empirical Mental Health, The National Guideline Clearinghouse, The Texas Algorithm Project, The Harvard Algorithm Project and SAMHSA, NIMH, Evidence Based Mental Health, Medline Abstracts and Evidence Based Clinical Reports. The keywords for this search were: Autism, Aspergers, Pervasive Development Disorders, Autistic Spectrum Disorder, Group Therapy, Evidence Based Therapy/Treatment/Interventions, Empirically Supported Therapy/Treatment or Interventions, Treatment Guidelines, Psychotherapy in numerous combinations.

The search provided very limited evidence-based protocols or manuals. There is a great deal of literature written and published on this topic. There are whole instituted, programs and systems targeting autism. Likewise, a great deal of information on the neurological substrates of autism, their behavioral correlates and the incidence and etiology is available. Most of this information is helping to clarify and further refine the interventions and prevention of autistic spectrum disorder. The importance of this topic is punctuated by the reported significant increase in the diagnosis and attending social/academic problems associated. In the 1970's the incidence was noted to be about 1 in 10000, now it is reported to be around one in a thousand. Infact, Simon Barron Cohen, one of the world experts cites that Asperger's Disorder and like patterns of behavior has reached incidences of 1 in 300. The diagnostic struggle to differentiate between Autism Disorder, High Functioning Autism and Asperger's let alone Pervasive Developmental Disorders NOS requires sharp clinical skills and evaluative focus. Sara Sparrow (2004), at the Brain and Development conference in Anchorage in May, 2004, stated quickly that after noting the DSM IV criteria (that is reliable, Mahoney, 1998) the difference between HFA and Asperger's is that the latter doesn't have friends and cares about it. Lastly, there were articles that, while not cited in this review, noted that many ASD individuals are diagnosed with schizophrenia, psychotic disorders and severe personality disorders. Caution then must to taken to clearly cluster the symptoms.

Group Therapy and Autistic Spectrum Disorders: Kabot et al, 2003, reviewing the scientific literature on evaluation and treatment, note that individual therapy and skill-individual focused therapy is primary. There is by extension, the ability to use group format in the essential component of parent training and support (Diggle, 2002). The goal of these groups and psychoeducational sessions is three fold: 1) to help the caregivers, through information, to deal with their own struggles and changes due to the diagnosis; 2) assist in direct skill and intervention so the parents can assume the role of therapist or co-therapist and 3) to learn how to advocate and problem solve for the needs of their child. This includes learning IEP, Government Rules, Agency Protocol and Legal Protections for their child.

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The symptoms of ASD preclude, at least initially, groups based on the dynamics underlying typical therapy. Socialization groups and communication skill generalization can be facilitated in group or environmental manners with high functioning or after successful individual interventions.

Individual Therapy and Autistic Spectrum Disorders: There was no simple evidence based practice model noted in this brief survey. Kabot et al, 2003, and the NIMH information brochure both outline principles that are strongly agreed upon by most experts. These are predominantly individual, intense and long term interventions. The first principle is that any and all interventions begin at the earliest possible time. (Erba, 2000) Since this is a developmental disorders and the process of functioning is directly related to age-stage milestones, the faster a thorough and accurate evaluation is completed and subsequent interventions initiated the more positive the outcome. Second, the agreement is that intensive interventions are the norm. The consensus is at least 20-25 hours weekly of systematic instruction for young autistic clients. Engagement by the client in a number of intense and enduring programming has been shown to be more effective. The more environments that the interventions bridge across the better. The third area of agreement is parent education and training. Using tools such as groups, psychoeducation and bibliotherapy, support and therapy for the caregivers are cited. Fourth, is particular focus on communication skill. These skill programs and interventions should be attempting to engage the client in attention tasks, reciprocal interaction and expression of needs. There are many technological based interventions on helping HFA and Asperger's to deal with nonverbal cues, facial recognition and the use of appropriate conversational language. The Fifth area is the use of Applied Behavioral Analysis. This helps to understand cues to the actions of the client, helps to sculpt interventions specifically to their strengths and decreases frustration on the part of caregivers. Finally, the principle of generalization is the goal. Every individual program must attempt to provide opportunity and skills to be able to negotiate changing environment and demands.

Tony Attwood (2001) and Klin (2000) both have written books on Asperger's. Individual therapy for the anxiety, depression and sometimes Obsessive Compulsive Behavior Disorder are appropriate. Both caution that the therapist must remember that these disorders are nested within the larger functioning pattern of Asperger's. The outcome is that for many in this and the HFA category, mainstream work and socialization (with ongoing encouragement) is a probably outcome.

Brief Therapy Models and Autistic Spectrum Disorders: There were no citations for brief therapy. Autism and PDD are not candidate disorders for brief therapy or intervention. In fact, the literature suggests a lifetime of support, case management, professional interventions and parental support.

Professional Status in Therapy: All therapist, interventionists and case managers must be thoroughly trained and capable to deal with this population. Educators, medical personnel and program administrators must be very familiar with this category if they are to maintain effectiveness, decrease compassion fatigue and push for inclusion. There were no specifics outside the evaluation for other psychiatric and psychological problems and necessitated significant academic credentials for many parts of the treatment program. Training, familiarity and appropriate structure seem to be adequate. Likewise, the parents must have a central decision making and therapeutic role in the intervention of most of the ASD clients.

Multi-Cultural Considerations: The literature on multi-cultural adaptation of evidence based treatments was less than complimentary. Nagayama Hall, 2001, reviewing the empirically supported literature plainly states: "there is not adequate empirical evidence that any of these empirically support therapies is effective with ethnic minority populations" (p.502). Bernal and Scharron-Del-Rio, (2001) earlier noted the same conclusion and called for a more "pluralistic" methodology in developing evidence based and culturally sensitive treatments. The overall consensus is that, even lacking specific cultural treatments, the application of evidence supported interventions is better than using non-supported techniques. There were no citations about cultural considerations directly related to this group. Family dynamics and worldview must be considered in the assignment of interventions. Since this group of disorders is very brain-based, the interventions appear to be universal.

Pharmacological Interventions: Medication are used not for the core problems but rather to deal with attending issues like aggression, tantrums, self harm. ADHD medications are used to help with attention issues, atypical antipsychotic are used in severe behavioral cases particularly risperidol. For Seizure, which is present in 1 of every four ASD clients, anticonvulsants are used regularly. For HFA and Asperger's, SSRIs have been used successfully for depression, anxiety and OCD. The strongest caveat is that ASD clients are

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more sensitive, have greater paradoxical reactions and difference response patterns than normal clients. Special attention by the multidisciplinary team to the effects of medications is important. Since the child can not always be vocal about the effects or side effects, behavioral reporting, incidence logging and slower titration are noted as best practice.

Manuals: None.

Literature Summary References:

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Nagayama Hall, GC. Psychotherapy Research with Ethnic Minorities Empirical , Ethical and Conceptual Issues. *Journal of Consulting and Clinical Psychology*, June 2001, Vol. 69, No. 3, 502-510

National Institute of Mental Health. Autism Spectrum Disorders (Pervasive Developmental Disorders). Detailed Booklet
www.nimh.nih.gov/publicat/autism

Other Resources used but not cited:

Pretending to be Normal: Living with Asperger's Syndrome by Liane Holliday Willey 2001

Pervasive Developmental Disorders: Finding a Diagnosis and Getting Help by Mitzi Waltz 1999

Understanding Other Minds 2nd Ed. By Simon Baron-Cohen et al. 2001

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Appendix C: Sample Treatment Plans

Treatment Plan for Autism, PDD and Mental Retardation

Behavioral Definitions/Symptoms:

- Qualitative impairment in social interaction to include impairment in the use of multiple nonverbal behaviors
- Failure to develop peer relationships appropriate to developmental level.
- Lack of social or emotional reciprocity
- Cognitive impairment
- Problems with memory and learning
- Adaptive behavior delay
- Motor skill defects
- Sensory integration problems

Summary List of Problems:

1. Deficits in communication, social skills, and social interests
2. Delays in behavior, academic performance, developmental milestones
3. Caregiver burnout
4. Insufficient problem solving skills leading to functional impairment
5. Disruptive Behaviors in multiple settings

Problem #1:

Deficits in communication, social skills, and social interests

Goals:

Provide opportunities for patient to improve communication, social skills, and develop social interests

Objectives:

1. Refer client to appropriate community based services within ____ time.
2. Client will attend ____ social skills group per ____ to improve social skills and encourage interest in his/her social environment.
3. Assist client and caregiver in identifying volunteer community groups that would be of interest to the client and would permit client participation and build positive community connections for the client.

Problem#2:

Delays in behavior, academic performance, developmental milestones

Goals:

Patient will perform or develop in these areas to fullest capacity given limitations

Objectives:

1. Case management will make referrals to appropriate community based services within _____ time.
2. Assessment results and intervention suggestions communicated with classroom teacher and school counselor.
3. Assist parents in coordinating school and mental health behavioral intervention plans.
4. Increase parent/caregiver skill in identifying environmental modifications or structure that will enhance client's functioning.

Problem #3:

Caregiver burnout

Goals:

Reduce Caregiver “burnout” and enhance caregiver’s capacity to coach/parent patient and advocate for patient in multiple systems.

Objectives:

1. Refer to parenting group for special needs children for emotional support, advice, advocacy strategies, etc.
2. Assist family in identifying appropriate community-based respite services and becoming eligible to access them.
3. Coach family in the development of a “family wellness plan” that addresses and assists in balancing physical, mental and spiritual areas of life.
4. Address family/parent grief and loss issues in individual, family and group therapy. Provide education regarding the potentially on-going nature of this grief as the client reaches/fails to reach new developmental milestones.

Problem #4:

Insufficient problem solving skills leading to functional impairment

Goals:

Assist patient in the development of strategies to solve daily problems in their environment

Objectives:

1. Refer client to developmentally appropriate social skills group.
2. Assist parent/caregiver in the development of “external brain” strategies to increase client functioning.

Problem #5:

Disruptive Behaviors in multiple settings

Goals:

Reduce disruptive behaviors

Patient and others in environment will remain safe

Objectives:

1. Parent/caregivers will complete _____ course in _____ time frame.
2. Parent and teacher will create behavioral management plan consistent with patient’s capacity, positive reinforcement strategies, etc.
3. Teach patient socially appropriate self-soothing skills.
4. Teach parents basic strategies of Applied Behavioral Analysis and interventions.