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Practice Guidelines In Working with Individuals Who Have Developmental Disabilities

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Introduction

Practice Guidelines are intended to assist providers and consumers in clinical decision-making and to improve care. They also document evidence available to determine appropriate care. Guidelines are not meant to dictate clinical practice but are evidence based and a good place to go for guidance in the treatment of mental health disorders. One needs to keep in mind that each consumer is an individual and that each provider has his or her own approach to delivery of care. Therefore, all treatment must be individualized to the patient. Good clinical judgment should be used in all situations and at times will supersede practice guidelines.

Providers should use these guidelines as a road map for effective evidence based care. We also intend consumers to use these guidelines to help them make choices about treatment decisions.

PBH will use practice guidelines and community standards to evaluate effectiveness and appropriateness of care. The utilization management unit will review cases with poor outcomes, over or under utilization, requests for non-standard services, and will conduct random reviews. The care will be evaluated by these guidelines. Payment for services may be declined if that service is deemed inappropriate.

The practice guidelines in developmental disabilities are based in part on (1) research-based knowledge, (2) professional standards, (3) professional ethics, and (4) professional judgment. These aforementioned elements are used by clinicians, providers, educators, managers, and policy-makers in their efforts to improve the services/supports and personal well-being of persons with developmental disabilities. Essential to those efforts is a good understanding of developmental disabilities and its commonly associated conditions.

These practice guidelines in developmental disabilities are organized into six sections. In Section I, practice guidelines in diagnosis and assessment of mental retardation, autism spectrum disorders, and associated conditions are presented. Section II outlines practice guidelines for autism spectrum disorder interventions. Section III describes practice guidelines in physical health, specifically health disparities, health risk behaviors, and women’s health. In Section IV, practice guidelines in mental health assessment and treatment as well as crisis management are presented. Sections V and VI provide practice guidelines in habilitation assessment and support, respectively. Finally, a guideline for consumers and their families is provided.
Section I:

Practice Guidelines in Diagnosis and Assessment
What is a Developmental Disability?

North Carolina General Statute 122C-3(12a) defines a developmental disability as "a severe, chronic disability of a person which:

- is attributable to a mental or physical impairment or combination of mental and physical impairments;
- is manifested before the person attains age 22, unless the disability is caused by traumatic head injury and is manifested after age 22;
- is likely to continue indefinitely;
- results in substantial functional limitations in three or more of the following area of major life activity:
  - self-care
  - receptive (understanding) and expressive language
  - learning
  - mobility (ability to move)
  - self-direction (motivation)
  - the capacity for independent living
  - economic self-sufficiency
- reflects the person's need for a combination or sequence of special, interdisciplinary, generic services, individual supports, or other forms of assistance which are of a lifelong or extended duration and are individually planned and coordinated;
- an individual from birth to age nine, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting at least three of the above "areas of major life activities," if the individual, without services and supports, has a high probability of meeting those criteria later in life."

What is Mental Retardation?

Prevalence

The estimated prevalence of mental retardation is approximately 1% of the population. There are slightly more males than females with mental retardation.

Etiology

The causes of mental retardation are diverse, including prenatal, peri-natal, and post-natal causes. Some common causes of mental retardation include:
• Genetic syndrome
• Metabolic disorder
• Maternal substance abuse
• Environmental factors
• Trauma or illness
• Unknown cause (as high as 40%)

**Common Characteristics**

There are several considerations that should be taken into account when providing supports and services to individuals with mental retardation/developmental disabilities. These include:

• Recognizing that disability is often associated with stigma, people with mental retardation do not want to be viewed as incapable, incompetent, or devalued. To minimize the stigma that may come with a label, some people with disabilities will try to cloak their disability, and pretend that they understand what you are asking, when in fact they may actually not fully understand the question, situation, consequences, etc. Edgerton (1968) referred to this characteristic as _Cloak of Competence_.

• **Acquiescence** – people with developmental disabilities often have a desire to please others perceived to be in power. They may respond to questions in a certain manner or direction because they think that is what is the “expected” or “desired” response. This tendency may often contribute to “acquiescence,” or the tendency to answer “yes” to questions.

• **Processing time** - people with developmental disabilities may require additional time to process a question and their response. Be aware of this and ensure that sufficient time is given for the person to respond.

• **Memory difficulties** - people with developmental disabilities may not recall long questions or the different elements of a complex sentence => this may lead to a tendency to repeat the last series of choices or repeat to the same response for several questions.

**Diagnosing Mental Retardation**

Historically, the American Association on Mental Retardation (AAMR) has led the field of mental retardation with its Manual on Terminology and Classification. The different Federal and State agencies as well as the American Psychiatric Association in its Diagnostic and Statistical Manual’s (DSM) diagnostic criteria of mental retardation have always adopted the AAMR definition of mental retardation. AAMR has updated the definition of mental retardation 10 times since 1908. Each update has reflected the then-current understanding of the condition currently referred to as mental retardation (MR).
AAMR published its latest *Diagnosis, Classification, and Systems of Supports Manual* in 2002 (Luckasson et al. 2002). The AAMR 2002 System (Luckasson et al, 2002) defined mental retardation as a disability characterized by significant limitations in both (1) intellectual functioning and in (2) adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18 (p. 1).

1. **Significant limitations in intellectual functioning** for diagnosing mental retardation is operationally defined as: ability level that is at least two standard deviations below the mean, considering the Standard Error of Measurement for the specific assessment instrument used and the instrument’s strengths and limitations.

2. **Significant limitations in adaptive functioning** for diagnosing mental retardation is operationally defined as: performance that is at least two standard deviations below the mean of either (a) one of the following three types of adaptive skills: conceptual, social, or practical; or (b) an overall score on a standardized measure of conceptual, social, and practical skills.

3. The **cutoff for onset is fixed at 18 years** because this age generally corresponds to the end of high school and the time when many persons assume adult roles.

Five important operational recommendations regarding Practice Guidelines are basic to this definition.

These are:

1. Limitations in present functioning must be considered within the context of community environments typical of the individual’s age peers and culture;

2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors;

3. Within an individual, limitations often coexist with strengths;

4. An important purpose of describing limitations is to develop a profile of needed supports; and

5. With appropriate supports over a sustained period, life functioning of the person with MR/ID generally will improve.

**Adaptive Behavior**

Based on extensive empirical work in the area of factorial structure of adaptive behavior, Luckasson et al. (2002) adopted the emerging consensus on the following multidimensional factor-cluster structure of adaptive behavior:
Conceptual Skills (cognitive and communication/academic skills) that involve receptive and expressive language, reading and writing skills, and handling money.

Practical Skills (independent living skills) that includes household chores, dressing, bathing, making food, vocational skills.

Social Skills (social competence skills) that involve friendship (formation and maintenance), interaction with others, social participation, social reasoning, comprehension, personal safety, following laws, and interpersonal gullibility.

Although not listed above, a fourth factor-cluster is found in many factor analytic studies of adaptive behavior: motor or physical competence (or development) that involves gross and fine motor skills, and ambulating.

The AAMR 2002 System’s theoretical model clarifies the key elements in understanding the individual’s functioning: the person, the environment, and supports. The five dimensions of AAMR’s multidimensional approach to defining and classifying mental retardation is based on the multiple influences on human functioning: intellectual abilities; adaptive behavior; participation, interaction, and social roles; health; and context. These are defined as follows:

- **Intelligence** is a general mental ability that includes reasoning, planning, solving problems, thinking abstractly, comprehending complex ideas, learning quickly, and learning from experience.

- **Adaptive behavior** is the collection of conceptual, social, and practical skills that have been learned by people in order to function in their everyday lives.

- **Participation and interaction** are best determined by directly observing one’s engagement in everyday activities and asking a simple question, “is the individual actively engaged with (attending to, interacting with, participating in) his or her environment?” **Social roles** refer to a set of valued activities normal for a specific age group.

- **Health** is a state of complete physical, mental, and social well-being. The health dimension also incorporates etiological factors associated with the condition of mental retardation. This definition of health is consistent with the definition used by the World Health Organization (WHO, 2001).

- **Context** describes the interrelated conditions within which people live their everyday lives and includes the immediate social setting including the person, family, and/or advocates; the neighborhood, community, or organization providing education or habilitation services or supports; and the overarching pattern of culture, society, larger populations, country, or sociopolitical influences (Bronfenbrenner, 1979). These various environments are important to people with MR because they frequently determine what individuals are doing, where they are doing it, when they are doing it, and with whom. Thus, these three environments can provide opportunities, foster well-being, and mediate systems of support.
The American Association on Mental Retardation moved away from levels of mental retardation (mild MR, moderate MR, Severe MR, Profound MR) in its 1992 Systems (Luckasson et al., 1992). This abandonment of the MR levels based solely on the individual’s IQ score was replaced by a multidimensional classification system (Luckasson et al., 2002). AAMR proposes to diagnose mental retardation as binary (yes/no). The classification of this complex condition is then based on the multidimensional aspects of functioning: limitations in intelligence, limitations in adaptive behavior, levels of support need, etiology, presence of mental health problems, health, etc.

Hence, an individual may have mental retardation with mild deficits in intellectual functioning, moderate deficits in adaptive behavior, unknown etiology, diabetes, bipolar disorder, and moderate overall level of support needs.

A Framework for Assessment and Planning Supports

The 2002 System presents a systematic framework for assessment and the use of supports to enhance personal outcomes. In that sense, it links assessment to intervention.

The framework for assessment involves three functions: diagnosis, classification, and planning supports. Each function has corresponding purposes and measures:

- For diagnosis, the primary purpose is to establish eligibility for services, benefits, or legal protections. The three required measures and tools are IQ tests, adaptive behavior scales, and documented age of onset.

- For classification, the purpose is to group for service reimbursement or funding, research, services, or communication about selected characteristics. Appropriate measures and tools include a supports intensity scale, IQ ranges or levels, special education categories, risk factors associated with certain conditions, or levels of adaptive behavior.

- For planning of supports, the primary purpose is to enhance personal outcomes related to independence, personal well-being, and school and community participation. Appropriate measures include self-appraisals, support intensity scales, and elements from an individual plan.

The concept of supports is integral to professional understanding and implementing the 2002 System. Since the mid-1980s, the supports paradigm has impacted education and rehabilitation programs in two ways. First, the focus on individualized supports has brought together the related practices of person-centered planning, personal growth and development opportunities, community inclusion, and self-determination. Second, the level and intensity of a person’s needed supports is
being used as the basis for agency and systemic planning and reimbursement patterns. Supports are defined as: “resources and strategies that aim to promote the development, education, interests, and personal well-being of a person and that enhance individual functioning. Services are one type of support provided by professionals” (AAMR (2002), p. 151)

**Measuring Support Needs**

As presented in the *Supports Intensity Scale User’s Manual* (Thompson et al., 2004) a comprehensive assessment of the pattern and intensity of support involves assessing the pattern of needed supports across six life activity areas (home living, community living, lifelong learning, employment, health and safety, and social), the area of protection and advocacy, and 15 exceptional medical and 13 exceptional behavioral support need conditions and behaviors. The evaluation is done on the basis of the frequency, daily support time, and type of support needed in reference to each of the activities/conditions/behaviors.

As one example of an instrument based on best practices the AAMR *Supports Intensity Scale* (Thompson et al., 2004) evaluates the pattern and profile of needed supports in the following areas:

**Part 1.** Life activity areas: home living, community living, lifelong learning, employment, health and safety, and social. A composite score (SIS Index Score) is derived from the sum of the scores obtained from these six life activity areas.

**Part 2.** Protection and advocacy activities related to advocating for self, managing money and personal finances, protecting self from exploitation, exercising legal responsibilities, belonging to and participating in self-advocacy/support organizations, obtaining legal services, making choices and decisions, and advocating for others.

**Part 3.** (a) Exceptional medical supports needs related to respiratory care, feeding assistance, skin care, and other conditions such as seizure management, dialysis, lifting and/or transferring, and therapy services. (b) Exceptional behavioral support needs related to externally directed destructiveness, self-directed destructiveness, inappropriate sexual behavior, and other conditions such as emotional outbursts, wandering, and substance abuse.

**Classification System**

Any system by which a person is diagnosed as having mental retardation and classified according to some level consists of a series of formalized rules specifying the characteristics that a person needs to possess in order to be so diagnosed and classified (Luckasson et al, 2002). The 2002 AAMR System considers classification of individual functioning according to their multidimensional system to be more informative and more helpful when planning services and supports for these individuals.

<table>
<thead>
<tr>
<th>Purpose of Classification</th>
<th>Dimension of Classification</th>
<th>Considerations for Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Service reimbursement or</td>
<td>• Intellectual Deficits</td>
<td>• Qualifications of examiner</td>
</tr>
</tbody>
</table>
Professional Judgment

Professional judgment is required in a number of situations such as when formal assessment is less than optimal, complex medical or behavioral conditions require multiple analyses, legal restrictions significantly impact opportunities to assess the person consistent with the five operational recommendations made earlier, and/or cultural or linguistic diversity impacts or effects the information needed for decisions.

The 2002 System emphasizes the importance of professional judgment and expands our understanding of its use as a critical part of best practices. Professional judgment is considered as a special type of judgment rooted in a high level of clinical expertise and professional experiences that emerge directly from extensive data. It is based on the professional’s explicit training, direct experience with the person with whom the clinician is working, and familiarity with the person and the person’s environment. Professional judgment is characterized by its being systematic (i.e., organized, sequential, and logical), formal (i.e., explicit and reasoned), and transparent (i.e., apparent and communicated clearly). Schalock and Luckasson (2005) specified that professional judgment involves the following six strategies: (a) conducting a thorough social history; (b) aligning data and its collection to the critical questions asked; (c) applying broad-based assessment strategies; (d) implementing best intervention strategies; (e) planning, implementing, and evaluating individualized supports; and (f) reflecting cultural competence and linguistic diversity.

Appendix A. Protection and Promotion of the Rights and Dignity of Persons with Mental Retardation

The Montreal Conference of the Pan-American Health & World Health Organizations on Intellectual Disability was held on October the 5th and 6th, 2004. This Conference was organized to develop a standard to which international organizations, states, and various social and civil actors could refer to in order to guide them in their endeavors aimed at insuring that the rights attendant to a full and complete citizenship are granted to persons with an intellectual disability.
This conference allowed experts in the field from the Americas to come together to discuss the state of fundamental civil rights accorded to individuals with intellectual disabilities throughout the world. It grew out of a desire to put intellectual disabilities on the international agenda by examining the impact of the work of the United Nations Ad Hoc Committee on an *International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities* on the everyday life of persons with an intellectual disability. Participants from 17 countries of the Americas unanimously adopted and endorsed the *Montreal Declaration on Intellectual Disabilities* (see Appendix A).

**Conditions Associated with Mental Retardation**

*Fragile x syndrome*

Fragile x syndrome is the most frequent cause of inherited mental retardation (Hagerman & Hagerman, 2002). Fragile x is also frequently associated with autism. It is estimated that approximately 20% of boys with fragile X meet the diagnostic criteria for autism.

The common features associated with fragile X include (Hagerman & Hagerman, 2002):

- mental impairment, ranging from learning disabilities to mental retardation.
- attention deficit and hyperactivity.
- anxiety and unstable mood.
- autistic behaviors.
- long face, large ears, flat feet.
- hyperextensible joints, especially fingers.
- seizures (epilepsy) affect about 25% of people with fragile X.

Cognitive, adaptive, and emotional functioning of girls with fragile x is typically less affected than boys (Batshaw, 1997). While most boys have mental retardation, only 33% to 50% of girls have significant intellectual impairment; the rest have either normal IQ or learning disabilities. Although many boys and some girls have some symptoms of autism, many tend to be very social and interested in other people.

Children and adults with mental retardation without a known etiology or autism should be screened for fragile x (Brown et al., 1996).

Individuals with Fragile x syndrome benefit from a structured and predictable environment and communication supports, much like individuals with autism spectrum disorders. The reader is referred to the sections on autism spectrum disorder in this document for more information relevant to treatment and habilitation needs of individuals with Fragile x syndrome.
**Down syndrome**

Down syndrome\(^1\) is the leading genetic cause (but, unlike fragile x, it is not inherited) of mental retardation. There are three types of chromosomal anomalies that lead to Down syndrome: trisomy 21 (the most common which explains approximately 95% of all cases), translocation (explains 4% of all cases), and mosaicism (explains 1% of all Down syndrome cases) (Bathsaw, 1997). Down syndrome is usually caused primarily by an error in cell division called nondisjunction. It is not known why this occurs. However, it is known that the error occurs at conception and is not related to anything the mother did during pregnancy.

Down syndrome occurs in 1 out of every 800 births (Gordin, Cohen & Hennekam, 2001). The risk of having a baby with Down syndrome increases with the mother’s chronological age (see Table below). Having said that, one must remember that 80% of all babies born with Down syndrome are born to mothers under the age of 35 years (Dykens, Hodapp, & Finucane, 2000).

**Table. Prevalence of cases of Down syndrome births by chronological age of mother (Kozma, 1986)**

<table>
<thead>
<tr>
<th>Mother’s Age</th>
<th>Prevalence Rate of Baby Born with Trisomy 21</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-24</td>
<td>1/1 450</td>
</tr>
<tr>
<td>25-29</td>
<td>1/1 350</td>
</tr>
<tr>
<td>30</td>
<td>1/885</td>
</tr>
<tr>
<td>32</td>
<td>1/725</td>
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<tr>
<td>34</td>
<td>1/465</td>
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<tr>
<td>35</td>
<td>1/365</td>
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<tr>
<td>36</td>
<td>1/290</td>
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<tr>
<td>38</td>
<td>1/175</td>
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<td>40</td>
<td>1/110</td>
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<td>42</td>
<td>1/70</td>
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<td>44</td>
<td>1/40</td>
</tr>
<tr>
<td>46</td>
<td>1/25</td>
</tr>
<tr>
<td>48</td>
<td>1/15</td>
</tr>
</tbody>
</table>

There are several physical characteristics associated with Down syndrome:

- short stature
- excess weight
- hypotonia
- almond-shaped eyes
- flat nasal bridge
- short neck

\(^1\) Some people call Down syndrome “mongolism” this is a pejorative term and should never be used.
Individuals with Down syndrome also present with co-occurring medical problems including (Batshaw, 1997):

- congenital heart defect 66%
- ophthalmologic disorders 60%
- hearing loss 60-80%
- hypothyroidism 30-50%
- dental problems 60-100%
- skin conditions 50%

It is important for individuals with Down syndrome to be closely followed by a medical team familiar with Down syndrome and associated health issues. Please see the sections on mental retardation for relevant habilitation resources for Down syndrome.

**Alzheimer type dementia and Down syndrome**

People with Down syndrome have higher rates of Alzheimer disease. A growing body of research suggests that people with Down syndrome also experience premature aging, perhaps as many as 20 years earlier than other adults. Many are in their mid to late 40s or early 50s when symptoms of dementia of Alzheimer type first appear. This compares to the late 60s for adults in the general population and for adults with mental retardation not related to Down syndrome (Janicki & Dalton, 2000). Not all adults with Down syndrome will exhibit Alzheimer disease - some may grow old free of any dementia.

Behavioral symptoms of Alzheimer's dementia may include, but are not limited to: (1) the development of seizures in previously unaffected individuals, (2) changes in personality, (3) long periods of inactivity or apathy, (4) hyperactive reflexes, (5) loss of activity of daily living skills, (6) visual retention deficits, (7) loss of speech, (8) disorientation, (9) increase in stereotyped behavior, and (10) abnormal neurological signs (Janicki, Heller, Seltzer & Hogg, 1995).

There is no single diagnostic test for Alzheimer's disease. If the presence of Alzheimer's disease is suspected, a complete physical examination and more frequent medical, neurological and psychological evaluations are strongly recommended to establish the progressive nature of the symptoms. However, universally applied screening instruments used with the general population, such as the Mini-Mental Status Examination, usually are not applicable to persons with mental retardation. This is due to the variability of cognitive abilities among people with mental retardation. The AAMR/ IASSID* guidelines for the diagnosis and care management of dementias offer guidance on how screening and evaluation can be carried out.

A definitive diagnosis can only be made at the time of autopsy. The numerous test and evaluation procedures currently employed result only in a possible or probable diagnosis of Alzheimer's disease.
For a probable diagnosis of Alzheimer's disease, it is necessary to observe a well-documented progression of symptoms. Complete evaluations must be performed periodically using the person's previous performance as the comparison measure. Such evaluations or tests are necessary to rule out conditions other than Alzheimer's disease, particularly reversible forms of dementia. A complete evaluation should include:

A detailed medical history.

A thorough physical and neurologic examination, including the testing of sensory-motor systems, to rule out other disorders.

A "mental status test" to evaluate orientation, attention, recent recall and the ability to calculate, read, write, name, copy a drawing, repeat, understand and make judgments.

A psychiatric assessment to rule out the presence of a psychiatric disorder, particularly depression.

Neuropsychological testing to measure a variety of functions that include memory, orientation, language skills, intellectual abilities and perception.

Routine laboratory tests, including blood work and urinalysis, and health screenings and other testing such as chest x-ray, electroencephalography (EEG) and electrocardiography (EKG), as well as certain specialized tests as deemed appropriate.

A good place to start for an evaluation of Alzheimer's disease is the person's physician. A neurologist, geriatrician or an internist can also be a valuable resource. States may have specialized centers for the evaluation and treatment of people with memory disorders, or Alzheimer's disease. These centers may provide geriatric evaluations and assessment procedures, in addition to other services. States may also have specialized services for people with mental retardation who are aging. These may include special clinics of local mental retardation, mental health or aging agencies, and university developmental disabilities programs.

Habituation recommendations following Alzheimer's diagnosis. Studies are showing that persons affected by Alzheimer's disease can continue to live in the community, if the right supports and assistance are provided. Many agencies have set up specialty teams that can provide advice and guidance to staff and families confronting care challenges. However, since persons affected by dementia may not be able to continue to live on their own, “dementia capable” housing and supports need to be provided. If such services are in place, admission to nursing facilities in older age can be prevented.

Once the suspicion of Alzheimer's disease has been clinically confirmed, the person's family, caregiver, or paid providers may need to make changes in the person's daily routine. First and foremost, the person must feel safe and secure in his or her environment. As a result of the complications associated with Alzheimer's disease, what may have been comfortable and familiar for the individual will become unrecognizable and may lead to unpredictable behavior.
Some tips for helping the person affected, as well as caregivers, cope with the effects of the disease include:

- Emphasize maintaining abilities, particularly those affecting dignity (e.g., toileting, eating), rather than trying to teach new skills.

- Keep changes in environment and daily routine to an absolute minimum.

- Simplify routines and reduce choices to minimize feelings of anxiety and frustration.

- Use patience and redirection, keep verbal requests simple, and provide general supportive care.

Many more tips are contained in the booklet, *Developmental Disabilities and Alzheimer's Disease: What You Should Know*, available from The Arc.

### Resources - Internet

Disability-related resources and technical information are available at the University of Illinois at Chicago's website at [http://www.uic.edu/orgs/rrtcamr/dementia.htm](http://www.uic.edu/orgs/rrtcamr/dementia.htm).

General information on Alzheimer's disease and local resources is available at [www.alz.org](http://www.alz.org).

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### Cerebral Palsy

Cerebral palsy (CP) is a non-progressive condition that is caused by an injury to the part of the brain that controls muscle tone (Pellegrino, 1997). *Cerebral* means having to do with the brain. *Palsy* means weakness or problems with using the muscles. Often the injury happens before birth, sometimes during delivery, or, soon after birth. Cerebral palsy can be mild, moderate, or severe. Mild CP may mean a child is clumsy. Moderate CP may mean the child walks with a limp. He or she may need a special leg brace or a cane. More severe CP can affect all parts of an individual's physical abilities and may in some cases cause them to be bedridden.

Cerebral palsy can be caused by exposure in utero to teratogens, genetic syndrome, chromosomal anomaly, asphyxia during delivery, sepsis at birth, meningitis, toxins or traumatic brain injury. Not everyone with cerebral palsy has co-occurring mental retardation.

There are four main types of cerebral palsy:

- **Spastic cerebral palsy** refers to when there is too much muscle tone or tightness. Movements are stiff, especially in the legs, arms, and/or back. This is the most common form of cerebral palsy.
• **Athetoid cerebral palsy** causes slow, writhing movements that the individual cannot control. The movements usually affect the person's hands, arms, feet, and legs. Sometimes the face and tongue are affected and the person has a hard time talking. Muscle tone can change from day to day and can vary even during a single day.

• **Ataxic cerebral palsy** refers to problems with balance and depth perception. They might be unsteady when they walk. They might have a hard time with quick movements or movements that need a lot of control, like writing. They might have a hard time controlling their hands or arms when they reach for something.

• **Mixed cerebral palsy** is a combination of spastic, athetoid, or ataxic CP. An individual with mixed CP might have both hypertonia and hypotonia. Some muscles are too tight, and others are too loose, creating a mix of stiffness and involuntary movements.

**Spina Bifida**

Spina bifida is the most common type of neural tube defect. It is a serious birth abnormality in which the spinal cord is malformed and lacks its usual protective skeletal and soft tissue coverings. The specific genes and environmental influences that contribute to the multi-factorial causes of spina bifida are not completely known. Spina bifida is only rarely associated with mental retardation.

An insufficiency of folic acid is known to be one influential nutritional factor (Kadir, Sabin, Whitlow, Brockbank, Economides, Alberman, & Noble, 1999). Recent public awareness for women of birthing age to increase consumption of folic acid has led to a dramatic decrease in the incidence of spina bifida. The National Institutes of Health have advocated the need for all women of childbearing age to make sure they're taking 400 micrograms of folic acid a day to reduce the likelihood of neural tube defects in their baby.

**Epilepsy**

The word “epilepsy” originates from the Greek language meaning to be seized, taken hold of, or attacked. Epilepsy constitutes a group of conditions that vary in presentation, age of onset, and prognosis (Brown, 2002). Brown described an epileptic seizure as a brief, usually unprovoked, stereotyped disturbance of consciousnesses, behavior, emotion, motor function or sensory perception that results from cortical neuronal (electrical) discharge. Epilepsy is the most common co-morbid medical condition associated with developmental disabilities (American Psychiatric Association, 2000). Epilepsy is generally diagnosed by examining a person's brain waves using an electrical encephalograph machine (EEG).

There are different types or forms of epileptic seizures either generalized (originates in electrical activity in both hemispheres) or partial (originates in only one hemisphere) [see Brown, 2002; page 136]:

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**Practice Guidelines in DD**
**Generalized Seizures**

**Atonic:** Generalized seizure characterized by a sudden loss of muscle tone causing the person to fall to the ground.

**Myoclonic:** Short, involuntary, symmetrical twitches of the arms, neck, shoulders, or legs - similar to those which most people experience as they fall asleep. Myoclonic seizures usually occur in the morning within an hour or so of waking.

**Tonic:** Diffuse increase in muscle tone - consciousness is altered for about 10 seconds, but the seizures do not progress to the clonic or jerking phase.

**Tonic-clonic seizure:** also called “grand mal” – generalized onset that occurs without warning. Tonic (stiffening) phase followed by clonic (jerking) phase. For tonic-clonic seizures with a focal onset, patient will usually get a warning (aura) and may also be experiencing simple partial or complex partial attacks.

**Absence:** the person briefly loses awareness (clouding of consciousness) and stares into space and makes an immediate recovery. During the attack the patient may blink their eyes. Sometimes absences can occur with great frequency, up to 100 times a day, and therefore it may be a serious problem, for instance when the person is in school and their condition goes unrecognized.

**Partial**

**Simple partial attacks:** characterized by remaining alert, conscious and knowing that the seizure is occurring. These types of attacks are often called auras, especially when they progress to more severe attacks. It is an advantage for the person to be able to communicate with those around them during the attack and, for instance, be able to tell people that the attack is not dangerous and that it will stop by itself.

**Complex partial attacks:** the person loses awareness and is, therefore, unable to communicate or remember what happened. It is often preceded by a simple partial attack. Because awareness is lost the person may stare into space or do automatic things like make teeth grinding, chewing, or lip-smacking movements, pick at clothing or nearby objects or get up and wander around in a confused manner. Attacks typically last a few minutes. These attacks can be embarrassing and socially disabling. Most complex partial attacks start in the temporal lobe but can also originate in the frontal lobe. They can be difficult to control with medication and are sometimes cured by surgery.

**Aggression associated with Seizure Activity**
There is some evidence that certain types of seizures (e.g., frontal lobe seizures) may be differentially related to certain involuntary aggressive or self-injurious behaviors (Gedye, 1989; 1992). Gedye hypothesized that for certain individuals some problem behavior might be involuntary and triggered by non-convulsive seizure activity that originates in the frontal or temporal lobe area. These types of non-convulsive seizures do not respond well to traditional anticonvulsant medication, making some of these behaviors difficult to treat (Gedye, 1992).

The estimation of prevalence in the general population is approximately less than 1%; however, as many as 30% of individuals with developmental disabilities also have epilepsy (Sunder, Gidal, Pellock, & Smith, 2004). Sunder and his colleagues indicate that the co-occurrence of epilepsy occurs more frequently in the more severely impaired: 20% co-morbid epilepsy in individuals with mild mental retardation versus 50% for individuals with severe-profound mental retardation.

**Fetal Alcohol Syndrome / Fetal Alcohol Effects**

Three decades ago, researchers clearly identified the consumption of alcohol during pregnancy as being associated with a spectrum of physical, cognitive, and behavioral characteristics on the newborn fetus. These characteristics can be grouped into two distinct categories: (a) Fetal Alcohol Syndrome (FAS) which is characterized by clear dysmorphic features, significant behavioral impairment (e.g., ADHD, behavior problems, etc.) and significant intellectual deficits (e.g., mental retardation); and (b) Fetal Alcohol Effects (FAE) which is characterized by a lesser pathological presentation and might include typical appearance, mild behavioral problems, and mild cognitive impairments (Batshaw & Conlon, 1997). These conditions are sometimes grouped under the umbrella terms of Alcohol Related Neurodevelopmental Disorder (ARND), Alcohol Related Birth Defects (ARBD), or more recently Fetal Alcohol Related Disorders (FARD).

**Prevalence**

The estimated prevalence of FAS is approximately 1-2 per 1,000 births whereas FAE has a greater estimated prevalence of 3-4 per 1,000 births. It is important to note that FAE and FAS is a preventable form of mental retardation.

**Characteristics**

Below is an abbreviated listing of some identified criteria/features associated with a diagnosis of FAS (Stratton, Howe, & Battaglia, 1996):

- Confirmed maternal alcohol consumption;
- Facial abnormalities (flat midface, flattened philtrum)
- Growth retardation (e.g., low birth weight, low weight gain, under weight)
- Evidence of CNS abnormalities (e.g., small head size, brain anomalies, microcephaly, etc.)
- Neurological signs of deficits (e.g., fine motor impairments, hearing loss, poor eye-hand coordination, etc.)

Some behavioral characteristics of FAS or to a lesser degree FAE:
• Learning difficulties
• Hyperactivity
• Poor impulse control
• Poor social perceptions
• Attention difficulties
• Social problem solving deficits

In an effort to inform the public, the US Surgeon General has mounted a campaign that includes the following information.

*Based on the current, best science available we now know the following:*

• Alcohol consumed during pregnancy increases the risk of alcohol related birth defects, including growth deficiencies, facial abnormalities, central nervous system impairment, behavioral disorders, and impaired intellectual development.

• No amount of alcohol consumption can be considered safe during pregnancy.

• Alcohol can damage a fetus at any stage of pregnancy. Damage can occur in the earliest weeks of pregnancy, even before a woman knows that she is pregnant.

• The cognitive deficits and behavioral problems resulting from prenatal alcohol exposure are life-long.

• Alcohol-related birth defects are completely preventable.

*Traumatic Brain Injury*

Traumatic Brain Injury (TBI) is defined as an insult to the brain caused by an external physical force that may produce a diminished or altered state of consciousness, which results in cognitive or physical impairment. These impairments may be either temporary or permanent and cause partial or total functional disability or psychosocial maladjustment. This term does not apply to brain injuries that are degenerative or congenital or are caused by birth trauma. A TBI can be caused by a blow or jolt to the head or the head striking an object. It can even be caused by child abuse (e.g., shaken baby syndrome), fall, bicycle or motor vehicle accident, or gunshot wound. Portions of the brain may be twisted or torn as it moves around inside the skull during a fall or collision, for example. A head injury can be either closed or open; more brain damage and sequelae are likely to occur if the brain swells or bleeds. The severity of the head injury is generally rated as mild, moderate, or severe. Traumatic Brain Injury is one type of Acquired Brain Injury (ABI). ABI is defined as an injury to the brain that is not hereditary, congenital or degenerative (e.g. stroke, anoxia).
The effects upon functioning from a traumatic head injury will depend on which areas of the brain are damaged. There can be physical changes ranging from the onset of migraines, seizures, muscular weakness or paralysis. Changes in intellectual functioning, memory, and concentration are the most common long-term consequences. Expressive and receptive language skills and comprehension may be affected. Changes in mental health and behavior after a brain injury can range from mood disorder, increased irritability and aggression, impulsive control, and/or altered personality (NC MH/DD/SAS Fact Sheet).

North Carolina General Statutes include traumatic head injury in their definition of developmental disability. A developmental disability is defined as a severe, chronic disability of a person which:

- Is caused by a mental or physical impairment or combination of mental and physical impairments;
- Occurs before the person is the age of 22 years, unless the disability is caused by a traumatic head injury and is sustained after the age of 22;
- Is likely to continue indefinitely;
- Results in difficulties in three or more areas of major life activities such as: self-care, communication, independent living, learning, mobility; employment, and self-direction.
Different Types of Brain Injuries

Acquired Brain Injuries

Traumatic Brain Injuries

Penetrating

Nonpenetrating

Other Brain Injuries:
- Congenital brain injuries
- Birth trauma
- Strokes
- Hydrocephalus
- Tumors
- Multiple Sclerosis
- Brain infections
- Toxic substances

Prevalence

Each year approximately 1 in every 25 children receives medical attention because of a head injury (see Michaud, Duhaime, & Lazar, 1997). Males are twice as likely as females to experience a traumatic head injury (Semrud-Clickman, 2001). It is estimated that approximately 1.4 million Americans each year sustain a TBI. Many of these head injuries are relatively minor and don’t result in any long lasting sequelae; however, as many as 50,000 people die each year from a TBI (Langlois et al., 2004) and as many as 6 to 7% (80,000 to 90,000) of these TBI accidents results in the onset of long-term or lifelong disability (Thurman et al. 1999).

More locally, in 2001 - 1,800 NC residents died from a TBI (a rate of 22.1/100,000 population). There were 4,600 TBI hospitalizations (a rate of 56.4/100,000; NC- State Center for Health Statistics Hospital Discharge Data).
What are Autism Spectrum Disorders?

Autism Spectrum Disorders

The term ‘Autism Spectrum Disorder” is not a diagnostic label but a commonly used category to include individuals who present some qualitative deficits in social interactions, communication skills, and restricted, repetitive or stereotypic patterns of behavior, interests or activities. Autism Spectrum Disorders is synonymous with Pervasive Developmental Disorder (PDD; Volkmar & Pauls, 2003) and encompasses autism (high and low functioning), Asperger syndrome, and Pervasive Developmental Disorder Not Otherwise Specified (PDD NOS).

Definition

Leo Kanner, a child psychiatrist, first identified and described autism in 1943. Kanner (1943) described eleven children in his practice and termed their shared syndrome as "early infantile autism." He described these children as being characterized by a preference for aloneness, accompanied by a disinterest in people, an obsessive desire for sameness in their environment, impairments in social communication, and a fascination for objects (Kanner, 1943; 1944). Autistic disorder is most frequently identified by the age of 2 to 3 years (Lotter, 1967). Concurrent to Kanner’s work, Hans Asperger (Asperger, 1944) reported on a very similar group of children. Originally written only in German, Asperger’s work was long ignored but gradually gained acknowledgment following the work of Lorna Wing (Wing, 1981). Asperger syndrome has come to be viewed as a mild variant of autistic disorder in relatively bright children (Gillberg & Gillberg, 1989).

Prevalence

Although the DSM-IV-TR (APA, 2000) states that the prevalence of autism is roughly 4 to 5 cases per 10,000 children, that statistic is a gross under-estimate according to currently held prevalence rates (Wing & Potter, 2002). The prevalence of autism spectrum disorders may have risen by 5 fold over the past 20 years. Fombonne, Simmons, Ford, Meltzer, and Goodman (2001) reported on a randomly selected and stratified sample of British children and found an estimated prevalence of Autism Spectrum Disorders of 26 per 10,000. Similar findings have been reported in a US sample of young children (Newschaffer, Falb, & Gurney, 2005; Yeargin-Allsopp et al., 2003). Why such a huge increase? The exact reasons are unknown but it is in part attributable to better and earlier diagnosis of the condition and a broadening of the diagnostic criteria.

Cause of Autism

Much about the cause or causes of autism are unknown. What can be ruled out are psychological trauma, bad parenting, physical abuse, and separation anxiety (Ritvo & Freeman, 1984). Much of the current research and speculation revolves around the functioning of the brain and its neurochemistry. Most researchers and clinicians agree that the causal factors have a neurological basis that affects cerebral functioning and have a strong genetic component (Volmar & Pauls, 2003). The strong genetic component is clearly demonstrated in the increased risk of autism.
in families who already have a child with autism (Bailey et al., 1995). Research efforts to elucidate the causes of autism are ongoing. Although the exact causes of autism elude us, promising treatment intervention programs exist which can improve the quality of life of many children with autism.

**Infant Immunization**

The recent increase in reported incidence in autism over the past several decades coincided with immunization schedules for young infants. Some parents had questioned whether there might be a link between these vaccines and the onset of autism in young infants. There have been two major concerns with respect to the possible causal link between infant immunizations and the onset of autism (particularly the regressive type). These concerns with infant vaccines center on: (1) the Measles-Mumps-Rubella vaccine and (2) thimerosal, a mercury based preservative found in many vaccines.

**Measles-Mumps-Rubella**

The most recent concern with the Measles-Mumps-Rubella vaccine was triggered by a paper published in the Lancet (Wakefield et al., 1998). Wakefield and his colleagues reported that they followed 12 children who presented with a loss of previously acquired skills and regression leading to eventual diagnosis of autism following MMR vaccination. These authors hypothesized that the live measles virus contained in the MMR vaccine lodging itself in the intestinal gut of these children leading to bowel problems and the release of toxins that caused a loss of neurological functioning and subsequent autism (Wakefield et al., 1998). Andrew Wakefield alarmed parents and pediatricians alike by dramatically calling for the suspension of the MMR vaccination.

Following this publication and statements made by the lead author, many parents around the world began refusing the MMR vaccinations for their typically developing infants. The onslaught of fear and uncertainty surrounding the MMR vaccination prompted the Centers for Disease Control and Prevention and the National Institutes of Health to mandate a thorough investigation. The Institute of Medicine (IOM) of the National Academy of Sciences was charged with the task of conducting an independent and comprehensive investigation of the evidence and to evaluate the hypothesized causal link between the MMR vaccine and the onset of autism.

The IOM’s 15-member panel concluded in their report that “the evidence favors rejection of a causal relationship at the population level between MMR and autism spectrum disorders” (National Academy of Sciences, 2001). These findings and conclusions were maintained and reiterated in a follow-up report examining more current data (NAS, 2004). There is no scientific evidence to support the hypothesis that the Measles-Mumps-Rubella (MMR) vaccine causes autism.

**Thimerosal**

Thimerosal, a compound containing ethylmercury, was used as a preserving agent in many vaccines (e.g., hepatitis B, influenza type B, diphtheria, etc.) since the early 1930s. It is important to
note that mercury accumulates in the human body because it has a long half-life and is not secreted. In 2001, the Food and Drug Administration (FDA) reported that they had calculated that an infant who complied with the recommended US childhood immunization schedule might be exposed to an accumulated level of mercury that exceeds the Environmental Protection Agency’s (EPA) recommended safety guidelines (Ball, Ball, & Pratt, 2001). The data from this FDA report was collected in 1999 and circulated previously. Although Ball and her colleagues never mentioned autism in their published paper and concluded that these levels were probably not harmful, they did express some concern with respect to the potential for mild neurodevelopmental effects in infants exposed to high levels of mercury. Following the initial report from Ball and her colleagues and citing potential neurotoxic effects from accumulated mercury levels derived from thimerosal in vaccines, the American Academy of Family Physicians, American Academy of Pediatrics, Advisory Committee on Immunization Practices, & United States Public Health Service issued a joint statement in 2000 calling for the removal of thimerosal from all vaccines. Since 1999, thimerosal has been removed from almost all infant vaccinations (IOM, 2004).

The IOM 15-member panel concluded in their report that “the evidence favors rejection of a causal relationship between thimerosal and autism spectrum disorders” (National Academy of Sciences, 2004). There is no scientific evidence to support the hypothesis that the thimerosal contained in childhood vaccines causes autism.

Many organizations, such as the Autism Society of America and the American Academy of Pediatrics, have official position statements encouraging parents to vaccinate their children.

**Autism**

Autistic disorder was first included in the DSM system about 15 years ago (DSM-III; APA, 1980; ICD-9; WHO, 1978) under the category of pervasive developmental disorders. The DSM-IV’s diagnostic criteria of autistic disorder focus on three main areas of functioning social skills, communication skills, and interests and activities.

We present below the areas of behavioral disturbance that are typically observed at various ages of development in the autistic child (see Table 1).

**Table 1. Areas of Disturbance Observed in Autistic Children (Tassé, Aman, Rojahn, & Kern, 1996)**

<table>
<thead>
<tr>
<th>Age</th>
<th>Sensory-Motor</th>
<th>Speech-Language</th>
<th>Relation to People / Objects and Events</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - 6 months</td>
<td>- quiet or fussy</td>
<td>- no vocalization</td>
<td>- no anticipatory social responses (absent or delayed in smiling response)</td>
</tr>
<tr>
<td></td>
<td>- persistent rocking</td>
<td>- crying, not related to needs</td>
<td>- poor or absent eye-contact</td>
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<tr>
<td></td>
<td>- startled or non-responsive to</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>stimuli</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- unusual sleep cycle</td>
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</tbody>
</table>
Individuals with autism are frequently characterized by mental retardation (estimated 75% co-morbidity). The “high” versus “low” functioning distinction made in autism is based on the individual’s cognitive skill level. Individuals with autism and no co-occurring mental retardation are referred to as “high functioning.” Some individuals with autism have demonstrated remarkable talents or skills (Hermelin & O’Connor, 1990; Kanner, 1943; 1944; Waterhouse, 1988; Young &

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Symptoms</th>
<th>Behavioral Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>6 - 12 months</td>
<td>- sleeping and eating cycles fail to develop</td>
<td>- fails to respond to mother's attention and crib toys</td>
</tr>
<tr>
<td></td>
<td>- uneven motor development</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- difficulty with transition to table foods</td>
<td></td>
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<tr>
<td></td>
<td>- failure to hold objects or attachment to unusual objects</td>
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</tr>
<tr>
<td></td>
<td>- appears to be deaf</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- preoccupation with fingers</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- over or under reaction to sensory stimuli</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- babbling may stop</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- does not imitate sounds, gestures, or expressions</td>
<td></td>
</tr>
<tr>
<td>12 - 24 months</td>
<td>- sleep cycle problems</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- loss of previously acquired skills</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- sensitivity to stimuli</td>
<td></td>
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<tr>
<td></td>
<td>- seeks repetitive stimulation</td>
<td></td>
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<tr>
<td></td>
<td>- stereotyped behavior</td>
<td></td>
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<tr>
<td></td>
<td>- mannerisms (e.g., hand-flapping, object twirling)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- no speech or occasional words</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- stops talking</td>
<td></td>
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<tr>
<td></td>
<td>- gestures do not develop</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- repeats sounds non-communicatively</td>
<td></td>
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<tr>
<td>24 - 36 months</td>
<td>- sleep cycle problems continue</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- refuses to do things which he appears capable of doing</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- delay in self-care skills</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- unusual sensitivity to stimuli &amp; mannerisms persist</td>
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<tr>
<td></td>
<td>- hypoactivity or hyperactivity</td>
<td></td>
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<tr>
<td></td>
<td>- mute or intermittent talking</td>
<td></td>
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<tr>
<td></td>
<td>- echolalia (e.g., repeats TV commercials)</td>
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</tr>
<tr>
<td></td>
<td>- specific cognitive abilities (e.g., good rote memory, puzzle skills)</td>
<td></td>
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<tr>
<td></td>
<td>- leads adult by hand to communicate needs</td>
<td></td>
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<tr>
<td>36 - 60 months</td>
<td>- continued disturbances in above areas with the exception</td>
<td></td>
</tr>
<tr>
<td></td>
<td>that sensitivity to stimuli &amp; mannerisms may decrease</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- no speech</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- echolalia</td>
<td></td>
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<tr>
<td></td>
<td>- pronoun reversal</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- abnormal tone and rhythm in speech</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- unusual thoughts</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- does not play with others</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- prefers to be alone</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- unusual use of toys (e.g., spins, flicks, lines up objects)</td>
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</tbody>
</table>
Nettelbeck, 1994). Individuals possessing these skills are commonly referred to as having savant skills. Individuals with autism and savant skills include numerous accomplishments including piano recitals, calendar calculations, mathematical calculations, artistic paintings or drawings, and feats of memory.

Within pervasive developmental disorders, there is also Rett’s disorder, disintegrative childhood disorder, Asperger’s disorder, and pervasive developmental disorder not otherwise specified.

**Rett's Disorder** is characterized by a regression of motor ability, deceleration of head growth, and the development of stereotypic hand gestures following a normal period of development during at least the first five months of an infant’s life (APA, 1994). Rett’s disorder is caused by a mutation of the MECp2 gene and is found almost exclusively in girls. It affects one in every 10,000 to 15,000 live female births. Most children with Rett’s disorder function in the severe to profound range of mental retardation. Rett’s disorder is considered a distinct neurological condition from Autism Spectrum Disorders and there is some discussion about whether or not it will continue to be included under PDD in the next revision of the DSM system.

**Disintegrative childhood disorder** is similar to Rett’s disorder in that it is characterized by a period of normal early infant development. However, unlike Rett’s disorder, disintegrative childhood disorder is diagnosed equally in boys and girls and the period of normal development is longer. Typically, onset occurs after at least two years of normal development (APA, 1994). Regression may include loss of previously acquired language, adaptive skills, bowel and bladder control, play or motor skills.

**Asperger’s Disorder** is characterized by impairments in reciprocal social interactions, stereotypic interests in specific topics, preference for routines, and motor clumsiness or stereotypies. Typically, there is good language ability overall but specific language peculiarities such as a superficially perfect language that may at times seem too formal, an inability to maintain a conversation, and poor non-verbal communication skills (Gillberg & Gillberg, 1991). Individuals with Asperger’s disorder present no significant deficits in intellectual and adaptive skills, but have marked impairment in social skills (APA, 1994). The main clinical challenge is making a differential diagnosis between high functioning autistic disorder and Asperger’s disorder. Szatmari (1991) found three substantive differences between high functioning autism and Asperger’s: social responsiveness, communication, and imaginative play. Individuals with Asperger's are more socially responsive to their parents/others, engage in more social behavior with peers, exhibit imaginary play, and display less echolalia and idiosyncratic speech (as children), although their speech may be perseverative or repetitive (Szatmari, 1991).

**Pervasive developmental disorders not otherwise specified (PDD-NOS)**; including atypical autism) is used when a person presents deficits in the three broad areas of PDD (social interaction, communication, and behavior and interests) but does not meet the diagnostic criteria for a specific PDD (APA, 2000).
**Practice Guidelines in Assessment of Autism Spectrum Disorders**

The American Academy of Neurology and the Child Neurology Society established an expert committee to review the literature and recommend practice parameters to screen and diagnose autism (Filipek et al., 2000). Filipek and colleagues concluded that, to ensure early intensive intervention, a dual process was needed: (1) routine developmental surveillance and screening specifically for autism performed on all children to identify which were at risk of any type of atypical development or specifically at risk for developing an autism spectrum disorder; (2) to differentially diagnose and evaluate autism.

Having an interdisciplinary team conduct the autism spectrum assessment is valuable and may include professionals from the following disciplines: speech pathologists, psychologists, pediatricians, education, occupational therapy, and physical therapy (National Research Council, 2001). Any effective and useful evaluation requires the professionals to talk to the family about their observations and primary concerns about their child (Marcus & Stone, 1993). Assessment methods should be individualized and selected based on the individual’s age, developmental level, communication skills, and identified areas of need. The assessment process may include:

- standardized assessment tools
- developmental history
- medical history
- parent interview
- review of existing records
- natural and structured observations of the child in multiple settings

**Early Detection/Screening of Autism**

Specific behavior signs in infants as young as 12 months can predict, with remarkable accuracy, whether a child will develop autism (Zwaigenbaum, Bryson, Rogers, Roberts, Brian, & Szatmari, 2005). Zwaigenbaum and his colleagues found that even at six months of age, there were certain behaviors that distinguished siblings later diagnosed with autism. These included a passive temperament and decreased activity level at age six months followed by extreme irritability, a tendency to fixate on objects, reduced social interaction, and lack of facial expression as they approached the age of 12 months. These researchers identified the following characteristics in infants later diagnosed with autism:

1. several specific behavioral markers, including atypical eye contact, visual tracking, orienting to name, imitation, social smiling, reactivity, social interest and affect, and sensory-oriented behaviors;
2. prolonged latency to disengage visual attention;
3. a characteristic pattern of early temperament, with marked passivity and decreased activity level at 6 months, followed by extreme distress reactions, a tendency to fixate on particular objects in the environment, and decreased expression of positive affect by 12 months; and
4. delayed expressive and receptive language.

Current screening procedures may not be effective in identifying children with milder forms of autism or those without co-occurring mental retardation or significant language delay (i.e., high functioning autism or Asperger’s disorder) (Filipek et al., 2000).

Diagnostic Assessment Instruments

The diagnosis of autism spectrum disorders is generally done by licensed professionals. The ability to diagnosis autism spectrum disorders has increased exponentially over the past 15 years. This increase in precision is attributable to the development of strong empirically derived assessment instruments such as the Autism Diagnostic Interview-Revised and the Autism Diagnostic and Observation System. In addition to these diagnostic instruments, we have gained a better understanding of the early stages of autism and are able to identify probable autism in infants as young as 12 months of age. The ADI-R and ADOS are currently considered the “Gold Standard” in establishing a diagnosis of autism spectrum disorders.

Autism Diagnostic Interview - Revised

The Autism Diagnostic Interview-Revised (ADI-R; Le Couteur, Lord, & Rutter, 2003) is a semi-structured, parent or caregiver interview to determine whether or not an individual meets the Diagnostic and Statistical Manual of Mental Disorders (3rd ed., revised) criteria for autism. The authors of the ADI-R plan to update the scoring procedure to reflect DSM-IV criteria. Although a home visit provides a chance to meet the child and to get a sense of the parents’ priorities, this interview may also be conducted as part of the in-clinic assessment (Rutter, Lord, & LeCouteur, 1990).

Used in research for decades, this comprehensive interview provides a thorough assessment of individuals suspected of having autism or other autism spectrum disorders. To administer the ADI-R, an experienced clinical interviewer questions a parent or caretaker who is familiar with the developmental history and current behavior of the individual being evaluated. The interview can be used to assess both children and adults, as long as their mental age is above 2 years, 0 months. Two studies (Lord, Rutter, & Le Couteur, 1994; Lord, Storoschuk, Rutter, R Pickles, 1993) were conducted to assess the psychometric properties of the ADI-R. Reliability was tested among 10 autistic (mean age 48.9 months) and 10 mentally handicapped or language-impaired children (mean age 50.1 months), and validity was tested among an additional 15 children with autism and 15 typically-developing children. Results indicated the ADI-R is a reliable and valid instrument for diagnosing autism.

Autism Diagnostic Observation Schedule

The Autism Diagnostic Observation Schedule (ADOS) (Lord, Rutter, DiLavore, & Risi, 2000) is a semi-structured observation scale for diagnosing autism spectrum disorders. This semi-structured assessment can be used to evaluate almost anyone suspected of having autism—from
toddlers to adults, from children with no speech to adults who are verbally fluent. The four modules of the ADOS provide a range of activities; the choice of module depends on the age and expressive language of the person being assessed. The ADOS consists of various activities that allow you to observe social and communication behaviors relevant to the diagnosis of pervasive developmental disorders. These activities are interesting and non-threatening and provide standard contexts for interaction. The ADOS activities may be least appropriate for adolescents and adults who are nonverbal. The four modules are used as follows:

Module 1: is used with children who do not consistently use phrase speech.

Module 2: is used with those who use phrase speech but are not verbally fluent.

Module 3: is used with verbally fluent children.

Module 4: is used with verbally fluent adolescents and adults.

The individual’s responses to the ADOS activities and prompts are coded and applied to a diagnostic algorithm. Only trained professionals can administer the ADOS. A two-day training is recommended to ensure administration proficiency on the ADOS.

Other Instruments that may be used in the Assessment of Autism Spectrum Disorders

*Autism Screening Instruments*

Most autism screening tools are designed to detect autism spectrum disorders concentrate on social and communication impairment in children 18 months of age and older, and focus on all three DSM-IV criteria for autism. There is a lack of validated autism screening tools for children under 18 months of age. Since autism screening ideally would follow a developmental screening that has indicated concerns, the administering clinician should directly observe the child in addition to using an autism screening tool questionnaire.


- **Modified Checklist for Autism in Toddlers (M-CHAT)** is an expanded American version of the CHAT and is used to screen for autism spectrum disorders in children ages 18-59 months.


- **Childhood Autism Rating Scale** is a brief rating scale that measures autism in children ages 2 years and older.

- **Gilliam Autism Rating Scale- 2 (GARS-2)** assists teachers, parents, and clinicians in identifying and diagnosing autism in individuals ages 3 through 22.


- **Pervasive Developmental Disorder Screening Test (PDDST-II Stage One)** is designed to screen for several autistic spectrum disorders in children as young as 18 months, including autistic disorder, pervasive developmental delay, and Asperger's disorder.


**Asperger Syndrome/HFA Screening Tools: (4 years to adult)**

Most Asperger Syndrome/high functioning autism (HFA) screening tools are designed for use with older children, and are used to differentiate these disorders from other autism spectrum disorders and/or other developmental disorders, such as mental retardation and language delays. These tools concentrate on social and behavioral impairment in children four years of age and older (up to adulthood), who usually develop without significant language delay. Qualitatively, these tools are quite different from the early childhood screening tools, highlighting more social/conversational and perseverative/behavioral concerns.

- **Autism Spectrum Screening Questionnaire (ASSQ)** The high-functioning Autism Spectrum Screening Questionnaire (ASSQ) is a 27-item checklist used to assess high-functioning autism spectrum disorders in children and adolescents with normal intelligence or mild mental retardation.


- **Social Communication Questionnaire (SCQ)**, formerly the Autism Screener Questionnaire (ASQ) screens for autism spectrum disorders in children ages 4 years and older (mental age of at least 2 years).


**Autism Assessment Instruments**

- The Psychoeducational Profile Revised (PEP-R) is an assessment and program planning tool for preschool and gradeschool-aged children with autism.

Section II:

Practice Guidelines for Interventions in Autism Spectrum Disorders
Interventions for Autism Spectrum Disorders

A good assessment should provide recommendations for intervention and teaching strategies. The learning style of each child or adult with autism is unique and varies over time and setting (Schreibman, Koegel, Charlop, & Egel, 1990). Transference of learning to everyday settings is of utmost importance and, for individuals with autism, requires careful planning. The individual with autism benefits most from learning opportunities that occur across all environments. The ultimate learning environment is one that integrates learning opportunities in the individual’s home, community, and school/work.

Treatment and Education of Autistic and related Communication handicapped Children (TEACCH)

The TEACCH program was founded in North Carolina in 1966 by Dr. Eric Schopler with the mission “To enable individuals with autism to function as meaningfully and as independently as possible in the community.” TEACCH's comprehensive classroom, residential, and vocational programs are geared towards individualized treatment inspired from behavioral principles (Reichler & Schopler, 1976). TEACCH focuses on structuring the learning environment (home, classroom, work, etc) to the deficits caused by autism, fostering independent functioning and avoiding frustration and behavior problems (Schopler, 1989). The TEACCH model aims to support the needs of families in whatever way makes the most sense for the family and the child. Structured teaching provides the primary basis for intervention in the TEACCH program (Lord, Bristol, & Schopler, 1993).

Schopler's work was heavily influenced by psychoeducational principles that emphasize parent involvement on an equal footing with a multidisciplinary treatment team. TEACCH maximizes treatment generalization and carry-over by enlisting parents as co-therapists. In the TEACCH program, parents are trained in behavior management principles and their role within their child's treatment evolves from trainee to trainer to emotional support and, finally, to social advocates (Mesibov, Schopler, & Sloan, 1983). The guiding principles of the TEACCH program are:

- To maximize adaptation by teaching new adaptive skills;
- To develop environmental modifications to accommodate the child’s deficit;
- To maintain parent-teacher collaboration;
- To provide continuity of structured teaching from preschool to adult years;
- To prevent behavior problems from developing.

The TEACCH-accredited classroom is typically in public schools in classes of no greater than 8 pupils. TEACCH classrooms are self-contained and separate from mainstream classrooms; however, children with autism in the TEACCH program can take part in appropriate regular classroom activities (McHale & Gamble, 1986). The teaching staff in these classrooms is carefully selected and extensively trained by TEACCH professionals.
The TEACCH curriculum is heavily influenced by the individualized assessment procedure (e.g., Psychoeducational Profile – Revised; PEP-R) with input from teacher observations and parent information. Olley (1986) presents a typical four-step process to developing an individualized treatment plan in a TEACCH program. The four-steps comprise:

1. Obtaining detailed information from individual assessment of the child's skills (both through naturalistic observations and informant-based questionnaires);
2. Interviewing the parents and obtaining their personal views regarding their child's skills and the parents’ desired results;
3. Assimilating the information obtained in the previous two steps and incorporating this information into specific curriculum objectives; and
4. Based on these objectives, designing a training curriculum.

Much of the curriculum selected is based not only on functional academic skills, but also on more general daily living skills with a general curriculum strategy focused on exploiting the child's strengths while working on skill deficits. TEACCH’s structured teaching caters to the individual’s visual processing strengths by using multimodal information presentation and relying heavily on visual aides. TEACCH structures the physical environment, individual tasks, time, etc. The physical environment is organized to reduce distractions and promote on-task behavior, tasks are structured to promote independent work, and time is structured using visual schedules which can also help reduce anxiety associated with knowing what the next activity is. Behavior problems are often managed by focusing on re-structuring tasks, demands, and environment, and focusing on the antecedents to the behavior.

For more information about TEACCH and resources, see their website: http://www.teacch.com/

Applied Behavior Analysis

The analysis of behavior has a long history in the field of developmental disabilities. There are two main branches: experimental and applied. The applied branch of behavior analysis includes a broad approach to the systematic study of behavior and individualized intervention to teach new adaptive behaviors and manage behavior problems. Applied behavior analysis (ABA) has been known under different names that include: behavior modification, operant conditioning, behavior management and, more recently, positive behavior supports. Applied behavior analysis refers to the use of principles of learning theory and applying these behavioral principles in order to enhance the development, abilities, and self-direction skills of individuals with developmental disabilities (Baer, Wolf, & Risley, 1968).

In the area of autism intervention, applied behavior analysis has come to be thought of as being only “discrete trial training” or Lovaas therapy. Discrete trial training is one example of applied behavior analysis methods but is not the only method of ABA. Functional assessment of
problem behavior is another technique within applied behavior analysis that has much value in intervention programs for individuals with autism and other developmental disabilities (functional behavior assessment is discussed later).

- **Applied Behavior Analysis (Discrete Trial Training)**

  Discrete trial training focuses on systematically teaching small, observable steps that comprise a skill. Skills for which the child demonstrates readiness to learn are broken down into small steps. Each step is taught by presenting an external stimulus or instruction (Lovaas, 1987). **Discrete trial training has strong research support; it is an evidence-based approach to teaching children with autism.**

  The [UCLA Young Autism Project](https://www.ucla.edu/youngautism) best illustrates this approach and was established by O. Ivar Lovaas in 1970 at UCLA. The main component involved intense one-on-one training for approximately 40 hours per week (Lovaas, 1987). Parents were intricately involved in the training program, which was carried out in the children’s homes, schools, or communities, with the collaboration of a team of undergraduate students who were supervised by graduate students.

  Lovaas (1987) geared this program to commence at an age no older than 46 months. Early enrollment into the UCLA program was essential to maximize the early childhood period of rapid development and learning. The UCLA young autism project uses discrete trials and positive reinforcement to shape and augment prosocial behavior, build receptive and expressive communication, and to suppress maladaptive behavior. During the first phase of the program, treatment focuses on receptive language and simple imitation. Phase two of the project involves teaching expressive language, making requests, early abstract language, and social interaction and cooperative play with peers. The third and final phase incorporates teaching the expression of emotions, functional academic skills (reading, writing, arithmetic), and social and conversation skills, and social rules and etiquette (Sallows & Graupner, 2005).

  After approximately 15 years of program operation and data collection, Lovaas presented the results of the UCLA Young Autism Project. Lovaas (1987) reported on 19 experimental subjects who went through at least two years of the intensive treatment program. Of the 19 autistic children in the treatment group 9 (47%) successfully entered and completed normal first grade and had a mean IQ of 107 (IQ range: 94 - 120); 8 (42%) were enrolled in aphasia classes, with a measured IQ ranging from IQ 56 to 95 (mean = 70); and the remaining 2 children (11%) were enrolled into autistic/mental retardation classes (IQ < 30). These impressive results, which seem to be maintained (McEachin, Smith, & Lovaas, 1993), have nonetheless attracted some skepticism regarding the selection criteria, pre- and post-treatment measures, and diagnostic criteria of the experimental group.

  In replicating the Lovaas (1987) study, Sheinkopf and Siegel (1998) reported on interventions based upon discrete trial training which resulted in significant gains in the children's IQ, as well as a reduction in autistic symptoms. Sallows and Graupner (2005) demonstrated that the Lovaas model could be implemented in a clinical setting outside a university with a similar sample and that the earlier findings regarding favorable outcome could be replicated. Following 2 to 4 years of intensive (40 hours per week) treatment, 11 of the 23 children (48%) achieved Full Scale IQs in
the average range, with IQ increases from 55 to 104, as well as increases in language and adaptive areas. At age 7, these rapid learners were succeeding in regular first or second grade classes, demonstrated generally average academic abilities, spoke fluently, and had peers with whom they played regularly. Sallows and Graupner reported that the strongest pretreatment predictors of success were: imitation, language, daily living skills, and socialization. Rapid acquisition of new material after 1 year was also a strong predictor. Low IQ (below 44) and absence of language (no words at 36 months) predicted limited progress. Intensity matters. Evidence suggests that 10 hours a week of discrete trial training is not adequate (Lovaas & Smith, 1988). There is evidence that children improve significantly with 20 hours a week (Anderson, Avery, DiPietro, Edwards, & Christian, 1987); however, there appears to be a dose-response relationship whereby children make greater gains with more intensive intervention.

Both the UCLA young autism project (discrete trial) and TEACCH place significant importance on acquiring and promoting language skills, which are fundamental to social interactions (Lovaas, 1977). However, since some children with autism, due to underlying biological/physiological deficits, are incapable of acquiring spoken language (Rutter, 1985), sign language or communication tools (e.g., picture board, Picture Exchange Systems) are incorporated into these programs as substitutes for verbal language. A second important variable in all of the early intervention programs discussed is age. The younger the child is entered into an intervention program, the greater the potential for gain. Having said that, much remains to be gained with good individualized interventions and supports for older children and adult individuals with autism spectrum disorders.

For more information on the Lovaas approach and resources, visit the Lovaas Institute, www.lovaas.com

Please see Appendix C: Revised Guidelines for Consumers of Applied Behavior Analysis Services to Individuals with Autism and Related Disorders

And Appendix D: Questions to ask a Behavior Analyst

_Floor Time_

Floor time is a developmental therapeutic approach developed by Stanley Greenspan, a child psychiatrist. Floor time (also known as Developmental, Individual difference, Relationship-based model; DIR) is described as a systematic intervention of working with the child to help that child go through the appropriate developmental stages of life (Greenspan & Wieder, 1998). For children with developmental disabilities this might include bringing the children to return to previously missed developmental stages.

Floor Time is based upon Greenspan’s theories of six functional milestones necessary for a child to succeed in further learning and development. According to Greenspan, these are:
1. The dual ability to take an interest in the sights, sounds and sensations of the world and to calm oneself down.

2. The ability to engage in relationships with other people.

3. The ability to engage in two-way communication with gestures.

4. The ability to create complex gestures, to string together a series of actions into an elaborate and deliberate problem-solving experience.

5. The ability to create ideas.

6. The ability to build bridges between ideas to make them reality-based and logical.

Typically floor time is one-on-one time between the child and a parent, or therapist in a play-like session of approximately 20 to 30 minutes. Greenspan asserts that this intensive one-on-one floor time may need to be carried out during multiple 30-minute sessions during most waking hours for children with severe developmental disabilities (Greenspan & Wieder, 1998). During floor time, the adult focuses on the following five steps:

1. Observation: listening and observing the child and get to understand the child's mood and style.

2. Approach: open the circle of communication: respond to the child’s communication by using gestures and/or words.

3. Follow the child's lead: do what the child indicates he/she wants you to do. Greenspan calls this “marching to your child’s drummer”.

4. Extend and expand: build upon the child’s themes and games, don’t direct play but follow it and move it further.

5. Child closes the circle: allow the child to initiate the end of a play activity, interaction or communication.

Floor time can be carried out by parents, older siblings, therapists, and other professionals. The goals are to be attentive to the child’s needs and lead making the child the focus of the playtime spent with them.

There have been no peer-reviewed, published studies evaluating the effectiveness of Greenspan’s floor time for children with autism.


**Relationship Development Intervention**

Relationship Development Intervention (RDI) was developed by Steven Gutstein, Ph.D. and is based on the philosophy that individuals with autism spectrum disorders can participate in authentic emotional relationships if they are exposed to them in a gradual, systematic way. RDI is a parent-based clinical treatment that addresses the core problems faced by all individuals with ASD, such as learning, friendship, empathy, and a love of sharing their world with others (inter-subjective engagement). The primary goal of the program is to systematically teach the motivation for and skills of “experience sharing” interaction, which proponents of this method claim is at the core of autism spectrum disorders.

RDI is a parent-based program developed to target deficits in Experience-Sharing in a systematic manner, resembling stages of typical development. RDI begins by evaluating the child’s Experience-Sharing competencies and obstacles to progress. Following evaluation, parents participate in a 6-day training phase, which includes introduction to theory, principles, and components of RDI, followed by thorough treatment planning and regular weekly or bi-weekly consultation meetings with a certified RDI consultant. Meetings include progress updates, discussion of goals, program planning, and review of specific videotaped segments of primary caregivers working with their child. Primary caregivers and children participate in intensive re-evaluation approximately every six months. At a later stage, children are placed with matched peers in weekly dyads and small groups. At the core of the program, primary caregivers learn how to perceive and scaffold opportunities for their child to respond in more flexible, thoughtful ways to novel, challenging, and increasingly unpredictable settings and problems. Primary caregivers are trained to incorporate these opportunities into their lifestyle, so that each day involves frequent, carefully framed opportunities presented seamlessly into the child’s routine. Because the primary agents in RDI are primary caregivers, this treatment program is highly cost effective.

One study evaluating RDI has been accepted for publication. Gutstein (in press) reported improvement in ADOS scores, diagnostic classification, and independent functioning in classrooms in children receiving RDI compared to children receiving other treatments. The RDI group, in contrast to the other therapy group, exhibited an improvement in social interaction and communication according to ADOS testing. The percent of children receiving RDI who attended regular education increased from 30% to 82% over the course of treatment (average 18 months). No such shift in education placement was found for children receiving other treatment. Because this study was conducted by the creator of RDI, it cannot be considered an independent validation of this approach. Also, these findings represent a small sample of relatively “high functioning” children with autism spectrum disorders and the groups were not matched or randomly assigned to type of treatment. Despite these limitations, this study offers preliminary support for the use of RDI as a treatment for autism. This treatment protocol averaged 9 hours per week of RDI intervention.

A second, unpublished, study extended these findings to include parent perceptions on the ADI-R and a measure of flexibility over the course of one year of RDI. Positive results were reported on ADOS, ADI-R, and on flexibility for 16 children diagnosed with an autism spectrum disorder. This study did not include a control, or other therapy comparison group. The average amount of therapist contact in this study was reported to be four hours per month.

For more information and RDI resources, see [www.rdiconnect.com](http://www.rdiconnect.com)
**Recommendations from the National Research Council’s Committee on Early Educational Interventions for Children with Autism**

At the request of the US Department of Education’s Office of Special Education Programs, The National Research Council formed the *Committee on Early Educational Interventions for Children with Autism*. This committee was chaired by Dr. Catherine Lord and consisted of a dozen prominent and internationally respected experts in the field of autism spectrum disorders. Their charge was to review the scientific literature and propose the Practice Guidelines for early intervention and education with respect to children with autism. Below is a summary of this committee’s conclusions and recommendations.

The National Research Council committee recommends that educational/intervention services begin as soon as the child is suspected of having an autism spectrum disorder. Those services should include a minimum of 25 hours per week, 12 months a year, in which the child is engaged in systematically planned, and developmentally appropriate educational activity toward identified objectives (National Research Council, 2001). They also recommend that each child receive sufficient individualized attention on a daily basis so that the educational objectives can be attained. This educational intervention should include particular focus on: functional spontaneous communication and social interaction delivered throughout the day in various settings, cognitive development and play skills, and prevention of problem behaviors. These interventions should, as much as it is possible, be carried out with typically developing peers.
Sensory Integration

Sensory integration defines behaviors of individuals with autism as functional attempts to regulate sensory stimulation (Ayers, 1972). Ayers, an occupational therapist, theorized that deficits in interpreting sensory information from the body and the environment stem from deficits in brain-behavior relationships. Sensory integration work is based on the idea that people with motor or sensory problems have difficulty processing the information their body receives through the various senses. Sensory integration therapy attempts to reduce these sensory disturbances related to touch, movement, and gravity. For example, in the case a child has a tactile-sensitivity problem (under- or over-sensitivity), brushing therapy is prescribed. This involves a brushing technique based on the use of firm strokes with a soft surgical brush on the child’s back, arms, and legs. Brushing is interspersed with joint compression, in which the elbows, arm sockets, knees, and hip joints are pushed together firmly several times in succession (also called deep joint compression therapy).

Sensory integration has some promise to help individuals with autism better regulate their sensory hyper- and hypo-sensitivity and better cope with sensory input. However, techniques such as Wilbarger and Wilbarger’s (1991) brushing therapy have failed to garner empirical support (Heflin & Simpson, 1998).
Section III

Practice Guidelines in Physical Health
Physical Health

Health Disparities

The health needs of persons with developmental disabilities are all too often overlooked. Developmental disability service providers have neither the education nor the mandate to assume responsibility for health promotion or healthcare. At the same time, public health practitioners have little education or awareness of the health needs of persons with developmental disabilities. However, a recent groundswell of research and policy efforts has focused attention on health and medical care disparities for this population. An entire section of Healthy People 2010 focused on disability and health. In his role as Surgeon General of the United States, David Satcher MD released a report entitled “Closing the Gap: A national blueprint to improve the health of persons with mental retardation” (Public Health Service, 2001). Dr. Satcher lamented that the health of individuals with mental retardation were not specifically addressed in Healthy People 2010 because appropriate surveillance data were missing for this population. He asserted that existing survey-based public health surveillance in the United States is inadequate for identifying people with mental retardation and other developmental disabilities. Dr. Satcher called for a national surveillance system that targets the health status and needs of people with developmental disabilities.

It is now recognized that a disability can often be complicated by additional medical, psychological, or environmental problems (Marge, 1988). Within the framework of health promotion for persons with disabilities, these additional health problems are referred to as secondary conditions (Frey, Szalda-Petree, Traci, & Seekins, 2001, Marge, 1988). Secondary conditions range from medical complications such as pressure sores and contractures to psychosocial adjustment problems to environmental issues such as access limitations (Seekins, 1991; Traci, Seekins, Szalda-Petree, & Ravesloot, 2002). During the last ten years, the prevention of secondary conditions in persons with disabilities has been a national goal of US service agencies, researchers, and policy makers.

Within this context and in recognition of the need to improve the quality of life of individuals with mental retardation, Special Olympics Inc. commissioned a report to examine the health needs of children and adults with mental retardation. This report outlined the lack of empirical information about chronic health conditions, health, and wellness among people with mental retardation (Horwitz, Kerker, Owens, & Zigler, 2000). The authors emphasized that research is needed to understand the extent to which chronic health conditions cause limitation and affect health and wellness in this population. The research that has been done suggests that, with few exceptions, the prevalence of chronic health conditions (including cardiovascular disease, cancer, lung conditions, diabetes) of individuals with mental retardation is similar to that of the general population (Hayden & Kim, 2002; Hayden & DePaepe, 1991, Frey, Szalda-Petree, Traci, & Seekins, 2001, Traci, Seekins, Szalda-Petree, & Ravesloot, 2002). Understanding the risk factors for

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secondary conditions and strategies for their prevention is important to people with disabilities, rehabilitation providers, and public health agencies.

In a study of secondary conditions among adults with developmental disabilities in Montana (Traci, Seekins, Szalda-Petree, & Ravesloot, 2002), limitations due to communication problems, physical fitness problems, low frustration tolerance, and weight problems were reported. The authors note that the problems associated with the most serious limitations involved significant behavioral or life-style issues. These data suggested that several secondary conditions might be targeted for interventions that could improve the health and quality of life of individuals with developmental disabilities while reducing medical care costs.

Research indicates that most individuals with developmental disabilities do not receive the services that their health conditions require. In fact, research on the access and quality of physical, mental, and dental health care demonstrates that individuals with mental retardation face barriers to health care, compared to the general population (Howells, 1986; Kastner, Walsh, & Criscione, 1994; Lennox & Kerr, 1997; Wilson & Haire, 1990). Research has demonstrated that many primary care providers are unprepared or otherwise reluctant to provide routine and emergency medical and dental care to people with developmental disabilities. Many providers refuse to serve, or limit the number of people served under the Medicaid program, a source of coverage for many people with developmental disabilities. Research has shown that individuals with mental retardation have four to six times more preventable mortality than individuals in the general population (Dupont & Mortenson, 1990; Harris & Barraclough, 1998) suggesting that appropriate medical care may alter the health trajectories of individuals with mental retardation.

In North Carolina, a study comparing the health and medical care of three groups of adults was conducted: adults with developmental disabilities, adults with other disabilities, and adults without disabilities (Havercamp, Scandlin, & Roth, 1994). The purpose of the study was to identify disparities in the health and medical care of adults with developmental disabilities and to compare the pattern of disparities with that of adults with other disabilities.

To briefly summarize the findings, adults with developmental disabilities reported the same or greater health risks compared to adults without disabilities. They were more likely to lead a sedentary lifestyle and eight times more likely to report inadequate emotional support. Similar rates of tobacco use and overweight /obesity were reported. For the most part, adults with developmental disabilities had the same or greater risk of chronic health conditions compared to adults without disabilities. Significant medical care utilization disparities were found for breast and cervical cancer screening as well as for oral healthcare. When compared to adults with other disabilities, adults with developmental disabilities presented a unique risk for inadequate emotional support and low utilization of breast and cervical cancer screenings.

**Health Risk Behaviors**

A risk factor is any physical, social, environmental, or behavioral factor that disposes a person to develop a chronic disease. Changing lifestyle behaviors and increasing access to health services can reduce the severity of, and potentially prevent, some major diseases and conditions. We
report the following risk factors for chronic health conditions: physical inactivity, tobacco use, obesity, and inadequate emotional support. These factors are discussed in turn.

**Physical Activity.** Regular physical activity can reduce the risk of developing many chronic conditions and lower the risk of disability and premature death. Individuals in the Disability group and the Developmental Disability group presented an increased rate of physical inactivity. These relative risks are compared to the No Disability population in North Carolina. A full 34% of adults with developmental disabilities reported that they had not engaged in physical activity at all in the past month. Increasing physical activity has been targeted as an objective of *Healthy Carolinians 2010*, the statewide implementation of *Healthy People 2010*.

**Tobacco Use.** Smoking is a leading cause of preventable death and leads to an increased risk for heart disease, stroke, lung cancer, and other respiratory diseases. A full 25% of the No Disability sample reported that they smoke tobacco products. Adults in the Disability group were more likely to smoke cigarettes compared to the No Disability group. Although adults with Developmental Disabilities reported the lowest smoking rates of the three groups (18%), they were not significantly different from adults with No Disability.

**Obesity.** Being overweight is a known risk factor for heart disease, stroke, hypertension, diabetes, and other chronic conditions. Adults in the Disability and Developmental Disability groups were relatively more likely to be overweight or obese compared to the No Disability group. In fact, 60% of adults with developmental disabilities were overweight or obese. *Healthy Carolinians 2010* targeted reducing obesity as an objective for adults in the general population of North Carolina.

**Inadequate Emotional Support.** Supportive relationships are helpful in coping with stress and in various life situations (Novack & Gage, 1995). In the general population, emotional support has been found to protect against health problems such as heart disease and depression (Cohen & Wills, 1985; House, Landis, & Umberson, 1998). Men and women with developmental disabilities are known to have significantly less emotional support than people in the general population (Rosen & Burchard, 1990; Sands, & Kozleski, 1994). The absence of emotional support has been found to correlate with poorer quality of life (Lunsky & Benson, 2001) and mental health problems (Meins, 1993; Reiss & Benson, 1985). In this study, an alarming 24% of adults with developmental disabilities reported that they had no one to talk to about personal things or often feels lonely.

Transportation and staffing limitations present unique barriers to interpersonal relationships as well as recreation and physical activities for adults with developmental disabilities. These barriers prevent adults from accessing available emotional support. For example, only 61.7% of adults with developmental disabilities reported that they could see their family whenever they wanted. Transportation or staffing limitations were cited as barriers to spending time with friends by 18.1% of adults. Transportation was identified in the Developmental Disabilities Act as one of eight areas of emphasis for Administration on Developmental Disabilities programs (The Developmental Disabilities Assistance and Bill of Rights Act, 2000).

It is estimated that approximately half of individuals with mild mental retardation do not access services in adulthood (Durkin & Stein, 1996; Landesman Ramey, Dossett & Echols, 1996;
Susser, 1968). Health promotion, disease prevention, early detection and universal access to care are the cornerstones of a balanced community health system. Individuals with developmental disabilities face barriers in each of these areas. The medical and dental care of those individuals residing in the community must be obtained from primary care providers in the community rather than relying on centralized institutional staff. Many health professionals have little exposure to individuals with developmental disabilities and, as a result, are sometimes uncomfortable treating them. In order to ensure access to quality services, there is a need for specialized training for health professionals. This need was recognized in the Developmental Disability Act first authorized in 1962. To meet this need, a nation-wide network of University Centers of Excellence on Developmental Disabilities: Research, Education, and Service was established. These findings indicate that more training is needed, especially for preventive and primary care providers. The Centers for Disease Control and Prevention funds programs on disability and health in 16 states and has recently entered into a cooperative agreement with the Association on University Centers on Disabilities to promote public health activities for persons with developmental disabilities.

Disparities were found in medical care utilization for adults with developmental disabilities as well as for other disabilities. High rates of poverty among individuals with developmental disabilities mean that many rely on publicly financed medical care insurance and services. People with developmental disabilities find that many providers avoid the program citing low reimbursement rates, administrative burden, and fear of being inundated with underfinanced patients who may require special time and attention. Dental care for adults is a particularly difficult matter in that, by and large, Medicaid does not cover adults’ dental care (Waldman & Perlman, 2002). Providers who are committed to treating individuals with developmental disabilities report that restrictive Medicaid regulations and reimbursement rates can limit innovative service models. Research is needed on the development of financing structures that better accommodate individuals with developmental disabilities. This research will depend on accurate health care utilization data.

Goals for health promotion include education regarding risks associated with various health behaviors as well as promoting a commitment to a healthy lifestyle. Research suggests a need for health promotion efforts focused on physical fitness, weight control, smoking cessation, emotional support, and disease prevention. Empirical research is needed to find educational approaches that are effective for individuals with developmental disabilities. The vast majority of individuals with developmental disabilities may not understand traditional strategies such as brief television or radio public service announcements and printed materials.

To be effective at promoting the health of persons with developmental disabilities, health promotion efforts must be specifically designed for that population. In many instances, it may be more effective to direct efforts at the developmental disability service delivery system. It is important that the staff members providing these services be educated and encouraged to support healthy lifestyles. Curricula could be offered on topics such as nutrition, physical activity, and tobacco use and provided to the residential, advocacy, and vocational service systems. In addition, health education and physical activity should be made an explicit part of special education curricula.
Women’s Health

The reproductive health of women with mental retardation and other developmental disabilities (MR/DD) has been terribly neglected. Often parents are uncomfortable discussing issues relevant to women’s health such as menstruation, gynecological exams, self-breast exams, mammograms, and sexuality. As a result, many women with MR/DD neither understand nor feel comfortable with their bodies and tend to take a passive role in their health care. They rarely participate in cancer screenings thereby missing opportunities for early detection of breast or cervical cancer.

The Women Be Healthy curriculum\(^3\) was developed to help women with mental retardation and other developmental disabilities to become more active participants in their health care\(^4\). The primary emphasis of the curriculum is on breast and cervical cancer prevention practices. The curriculum focuses on three components to help women become more informed health advocates: (1) health education, (2) anxiety reduction, and (3) assertiveness and empowerment training.

First, women learn about general health issues, their bodies, hygiene, breast self-examinations, as well as clinical procedures of breast exam, gynecological exam, and mammogram. Women are educated through verbal instruction, pictures, video, and hands-on experience. Anxiety about breast and gynecological exams is reduced through progressive exposure to the medical exam instruments, procedures, and setting. In addition, women learn effective ways of coping with mild discomfort or pain that they could experience during a gynecological exam. Relaxation techniques are taught and practiced throughout the curriculum. Finally, women are given the opportunity to role-play various women’s health situations in which they must assert themselves (e.g., asking the doctor a health-related question, describing their symptoms to a trusted person). In this manner, they are empowered to take care of their own health and identify and solve health-related problems.

The Women Be Healthy curriculum is presented in a small group format in eight weekly sessions. Participants are encouraged to bring a female staff or family member with them to the group meetings. These “guests” provide support to the participants during group meetings, help the women practice the skills between sessions, and are available to respond to health questions and concerns after the curriculum ends.

The effectiveness of the Women Be Healthy curriculum was first demonstrated by Lunsky, Straiko, and Armstrong (2002). These authors gathered pre- and post-group assessments on 22 women with mental retardation, 16 of these women also completed a 10-week follow-up


\(^4\) The Women Be Healthy curriculum is available free of charge through the North Carolina Office on Disability and Health. Contact Pam Dickens at (919) 966-0871, pam_dickens@unc.edu.
assessment. The assessment instrument measured health knowledge, healthy behavior beliefs, and coping strategies. The women demonstrated significant gains after participating in the curriculum and these gains were maintained at the 10-week follow-up.
Section IV

Practice Guidelines in Mental Health
Mental Health

Mental health problems are more prevalent in persons with developmental disabilities than in the general population. Estimates of the frequency of dual diagnosis (co-occurrence of developmental disabilities and mental health problems) vary widely; however, many professionals estimate that 30-35% of all persons with intellectual disabilities have a psychiatric disorder (Rojahn & Tassé, 1996). People with MR experience the full range of mental health problems, including anxiety disorders, mood disorders, schizophrenia, personality disorders, substance-related disorders, and sexual disorders (Reiss, 1994). Individuals of all ages and levels of functioning are vulnerable to mental health problems (Benson, 1985; Borthwick-Duffy, 1994). As many as one-third of all individuals with MR have a mental health or behavior problem requiring specialized mental health services (Einfeld & Tonge, 1996; Emerson, 2003; Reiss, 1994; Rojahn & Tassé, 1996; Rutter, Tizard, Yule, Graham, & Whitmore, 1976).

Mental health and behavior problems are the primary reason that individuals with are maintained in institutional facilities or lose community placements (Bruininks, Hill, & Morreau, 1988; Hill & Bruininks, 1984; Lakin, Hill, Hauber, Bruininks, & Heal, 1983). Researchers have shown the increased stress and burden on families caring for a child or adult with mental health problems (Hastings & Beck, 2004; Maes, Broekman, Dosen, & Nauts, 2003; McIntyre, Blacher, & Baker, 2002). Individuals with co-occurring mental health problems often face more obstacles to service and acceptance by community service providers than their peers without a dual diagnosis (Scheerenberger, 1983). Many people lose access to some health care services when they are relocated from institutions to the community (Day, 1992; Kastner, Walsh, & Criscione, 1994).

Unlike in the general population, the individual with MR is not likely to self-refer for a mental health evaluation. It is more likely to be a family member, direct-support personnel, job coach, teacher, or other person who will notice changes in the individual’s behavior and bring them for an evaluation (Nezu, Nezu, & Gill-Weiss, 1992). Hence, it is important that training in the area of mental health and behavior problems be carried out with family members as well as vertically through all levels of service providers.

Mental Health Assessment

There are significant barriers to appropriate and effective mental health evaluations for individuals with MR. These barriers include the individual’s limited ability to self-report symptoms and the need to rely on third-party sources, improper use of psychiatric medications, and a paucity of professionals (e.g., nurses, general practitioners, psychiatrists, psychologists, social workers) trained to work with individuals who present both MR and mental health problems. Providing professionals with specific specialized training in the area of psychiatric disorders in individuals with MR increases the likelihood that they will make an accurate diagnosis (Day, 1992, 1994; King, Szymanski, & Weisblatt, 1995). Tsiantis and colleagues (2004) reported positive changes in knowledge and attitude of direct support personnel towards mental health problems in individuals with MR after participating in Holt and Bouras’ (1997) structured training curriculum.

Symptoms are expressed differently in individuals with severe to profound MR (Day, 1994; Sovner & Hurley, 1999). The diagnostic reliability of psychiatric disorders drops as the individual’s
level of cognitive and language abilities diminish (Moss, Bouras, & Holt, 2000). The usefulness of current diagnostic systems is hampered when working with individuals with significant cognitive and communication impairments since many of the symptoms require some form of self-report on the part of the patient. Sturmey (1999) presented a table where he listed several potential problems in applying the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition criteria for major depressive disorder to these individuals.

In an effort to improve the quality of mental health evaluations, Deb, Matthews, Holt, and Bouras (2001) published practice guidelines in the area of assessment and diagnosis of mental health problems in adults with MR. The Royal College of Psychiatrists (2001) also published the Diagnostic Criteria for Adults with Intellectual Disabilities (DC-LD). This publication provides guidance in the process of diagnosing mental health problems in adults with moderate to profound MR. It is expected that professionals can continue to use the International Classification of Diseases-10th Edition (ICD-10; World Health Organization, 1992) or DSM-IV-TR when diagnosing mental health problems in individuals with mild MR.

The NADD (the National Association for the Dually Diagnosed) is currently working on a companion document to the DSM-IV-TR (APA, 2000). This document, entitled Diagnostic Manual for People with People with Intellectual Disabilities, covers all psychiatric disorders found in the DSM-IV-TR and attempts to address any diagnostic issue related to the applicability of the DSM-IV-TR criteria to individuals with MR. The NADD monograph reviews existing research and proposes modifications to the DSM-IV-TR criteria for children and adults with mild-moderate or severe-profound MR (Fletcher, Stravakaki, First, & Loschen, 2004). This reference is expected to be published in 2007.

Some clinicians have also proposed using certain behaviors as equivalents or substitutes to DSM-IV-TR/ICD-10 signs and symptoms when attempting to establish certain mental health diagnoses in individuals with MR (Lowry & Sovner, 1992). Others have reported that the empirical evidence is still lacking to support the use of behavioral equivalents (Ross & Oliver, 2003; Tsiouris, Mann, Patti, & Sturmey, 2003). Maintaining an open and skeptical attitude with constant re-evaluation of the working diagnosis is a priority in providing good care to individuals with MR (Ruedrich & Hurley, 2001).

**Interdisciplinary and Multi-Method**

On the one hand, there are signs and symptoms experienced by individuals with MR that are clearly attributable to a specific psychiatric disorder defined by the DSM-IV-TR or ICD-10. On the other hand, behavior problems can also be caused or maintained by environmental factors (discussed later in the functional behavioral assessment section). And yet again, in other cases, behavior problems might be associated with the onset or exacerbation of a psychiatric disorder (Sovner, 1986). Mental health and behavior problems may also be related to the onset of a medical condition (e.g., ear infection, ulcer, diabetes, seizure disorder, thyroid disorder). Mental health problems in individuals with MR are caused or maintained by multiple factors. These multiple factors might relate to biology, physical environment, social environment, life experiences, psychology, or any combination thereof. As such, using an interdisciplinary and multi-method assessment approach to effectively assess and diagnose mental health problems in individuals with MR is most recommended (Ferron, Kern, Hanson, & Wiesler, 1999; Deb et al., 2001).
An interdisciplinary team is critical in ensuring coverage of all possible factors when assessing the individual’s mental health problems. The *American Journal on Mental Retardation* published a special issue in 2000 (Rush & Frances, 2000) reporting on Expert Consensus Guidelines in the area of psychiatric and behavior problems in individuals with MR. Rush and Frances’ Expert Consensus Guidelines surrounding the assessment process detailed a multi-method approach including:

- Review of existing records
- Personal history (e.g., recording of recent stressors)
- Interviews with the individuals themselves, family members, and direct-support personnel
- Physical examination and medical history (blood test, blood pressure, documentation of etiology of MR)
- Medication and side-effects evaluation (e.g., medication toxicity screen, review of recent medication changes)
- Psychiatric assessment (e.g., unstructured diagnostic interview or standardized assessment instruments)
- Functional Behavioral Assessment (e.g., O’Neill et al., 1999)
- Direct observations (e.g., A-B-C observations, scatter plots)

Gardner and his colleagues have presented a comprehensive approach to the assessment of mental health and behavior problems that they’ve termed *multi-modal* (Gardner and Sovner, 1994; Gardner and Whalen, 1996; Griffiths, Gardner, & Nugent, 1998). The multi-modal approach attempts to explain the possible inter-relationship between biological, psychological, social, and environmental factors. In some cases the individual’s mental health problem may instigate more serious or frequent behavior problems. Gardner and his colleagues have proposed that under certain conditions some individuals may exhibit behavior problems to regulate mental distress caused by a mental health problem. Hence, treating the mental health problem will resolve the behavior problems as well.

Next, we briefly describe several important aspects when conducting a comprehensive interdisciplinary multi-modal assessment of mental health problems, including: medical problems that can sometimes be associated with mental health problems, clinical assessment of mental health problems, functional behavior assessment, and psychosocial stressors.

**Medical Problems Associated with Changes in Mental Health**

Medical problems can sometimes mimic certain symptoms of a mental health problem or result in a worsening of behavior problems (Gunsett, Mulick, Fernald, & Martin, 1989; Sovner & Hurley, 1983). It has been well documented that there is a disparity in healthcare services for individuals with MR and that many medical problems in this population are under-diagnosed (Beange, McEllduff, & Baker, 1995; U.S. Public Health Service, 2001). Certain medical conditions such as headaches, migraines, inner ear infections, urinary tract infections, ulcers, GI problems, thyroid problems, and seizure disorders need to be ruled out during a comprehensive evaluation of mental health and behavior problems.
The individual’s medication may also be a contributing factor to the onset or worsening of mental health or behavior problems. It is well recognized that individuals with MR may have unexpected reactions, side effects, or interaction effects to psychotropic medications (Reiss & Aman, 1998). Verhoeven, Sijben, and Tuinier (2004) reported that as many as 15% of referred individuals with MR presented signs of behavioral toxicity resulting from their psychotropic medication.

**Clinical Interviews**

Sovner (1986) used the terms *baseline exaggeration, intellectual distortion, psychosocial masking,* and *cognitive disintegration* to describe the primary difficulties in interpreting symptoms during the mental health interview. Another diagnostic challenge coined *diagnostic overshadowing* is the tendency of clinicians to interpret signs of coexisting psychiatric problems as an inherent feature of the mental retardation (Reiss, Levitan, & Szysko, 1982). It is crucial that symptoms be interpreted within the context of the developmental delay. It is important to have reliable descriptions of the individual’s premorbid functioning; every effort should be made to obtain previous developmental, medical, and psychological assessments. The person making the referral should be present at the assessment.

Effective interviewing of the person with developmental disabilities necessitates several considerations (Hurley, Levitas, Lecavalier, Pary, & King, in press; Perry, 2004; Tassé, Schalock, Thompson, & Wehmeyer, 2005). Responses can be affected by the style and format of the questions. Questions should be short, simple, unambiguous, and abstract concepts should be avoided. The validity of responses should be evaluated within the context of potential response biases such as responsiveness, acquiescence, and consistency. Clinicians need to frequently verify the individual’s comprehension and be aware that many individuals with MR may attempt to hide or minimize their disability, a phenomenon known as *cloak of competence* (Edgerton, 1967). These adaptations to the standard clinical interview obviously necessitate extra time and patience.

**Standardized Rating Instruments**

Standardized assessment tools have an important place in the diagnostic process. These tools can take the form of rating scales or interviews where information is obtained directly from the person with MR or from a third party. The *Psychiatric Assessment Schedule for Adults With a Developmental Disability* (PAS-ADD) represents a combination of these modalities. It is a multi-component standardized assessment tool measuring commonly occurring Axis I disorders. The PAS-ADD schedules consist of four different instruments, namely a semi-structured clinical interview for use with individuals with MR or third-party informants (Moss, Patel, Prosser, Goldberg, Simpson, Rowe, 1993), a mental health symptom and life-events checklist for use by direct support professionals and families (Moss, Prosser, Costello, Simpson, Patel, Rowe, et al., 1998), and a tool allowing to collect relevant information on mental health symptoms with or without the need for clinical interviewing (Mini-PAS-ADD; Moss, 2002).

Informant-based rating scales can be classified according to several dimensions, such as their content (broad or specific) and intended population (age and level of functioning). Some broad
measures such as the Reiss Screen for Maladaptive Behavior (Reiss, 1988) and the Assessment of Dual Diagnosis (Matson, 1997) are diagnostic in nature and based on established taxonomies. Other broadband measures were developed from empirical studies and do not necessarily align with established diagnostic categories. Examples of such scales would include the Aberrant Behavior Checklist (Aman & Singh, 1994), the Diagnostic Assessment for the Severely Handicapped-II (Matson, 1995), the Developmental Behavioral Checklist (Einfeld & Tonge, 2002), and the Nisonger Child Behavior Rating Form (Aman, Tassé, Rojahn, & Hammer, 1996). The Anxiety, Depression and Mood Scale (ADAMS; Esbensen, Rojahn, Aman, & Rucdrich, 2003) is an example of a specific purpose informant rating scale. The selection of an instrument hinges on the objectives of the assessment and on scale characteristics. Close attention should be paid to psychometric characteristics and population parameters when selecting an assessment instrument.

A number of self-report instruments have been used to measure mood and anxiety. Some of these instruments were developed specifically for people with MR, while others were developed for typically developing people and adapted for individuals with MR. For instance, the Self-Report Depression Scale (SRDQ) was designed specifically for adolescents and adults with mild to severe MR (Reynolds and Baker, 1988), whereas the Beck Depression Inventory (Beck & Steer, 1993) and the Zung Self-Rating Anxiety Scale (Zung, 1971) have been adapted and used as self-report measures with individuals with MR. Self-report measures should also be evaluated in terms of their reliability and validity. The response biases mentioned earlier in the context of interviewing should be considered when judging the validity of the obtained information. Questions with abstract or socially reflexive content, as well as those requiring comparisons or quantitative judgments, can prove difficult for some individuals with MR (see Finlay & Lyons, 2001). Obtaining clinical information using a multi-method approach and multiple informants will increase the reliability of the mental health diagnoses.

Functional Behavior Assessment

Behavior problems are often the reason for referrals for mental health assessments. As stated previously, the relationship between behavior and mental health problems is a complex one. For instance, aggressive behaviors have been associated with mood, anxiety, and psychotic disorders, but they have also been shown to be maintained by environmental contingencies (Hurley et al., in press). A functional assessment (FA) is an essential component of many mental health assessments. FA refers to a process used to identify variables that impact the occurrence of behaviors. FA techniques could be divided into three general categories, namely indirect, descriptive, and analogue assessments. These techniques are briefly described below. For more detailed reviews of FA techniques and data collection and observation systems, the reader can consult Linscheid, Iwata, and Foxx (1996), Sturmey and Bernstein (2005), and Mayville and Mayville (2005).

Indirect Assessments

Indirect assessment techniques are those where data is obtained through third-party reports. They take the form of interviews and rating scales, where informants are asked to recall previous observations and draw conclusions about the factors that cause and/or maintain the target behavior. Examples of FA interviews can be found in O’Neill, Horner, Albin, Storey, and Sprague (1999) and Reed, Thomas, Sprague, and Horner (1997). It should be noted that little research is available on the validity of the information obtained through interviews.
The Motivational Assessment Scale (MAS; Durand & Crimmins, 1988) and Questions About Behavioral Functions (QABF; Matson & Vollmer, 1995) are two widely-used rating scales that attempt to isolate variables maintaining behavior problems. Poor reliability has been reported for the MAS (Sturmey, 1994; Zarcone, Rodgers, Iwata, Rourke, & Dorsey, 1991) but recent studies have suggested good psychometric properties for the QABF (Paclawskyj, Matson, Rush, Smalls, & Vollmer, 2000, 2001). Several studies have indicated inconsistencies between rating scales and direct observations. For instance, Paclawskyj et al. (2001) reported that the MAS and QABF tapped similar content domains, but did not correspond well to analogue sessions.

Despite the problems with validity and reliability, there is a widespread use of non-experimental methods (Desrochers, Hile, & Williams-Moseley, 1997). They are quick, inexpensive, and can provide initial information to form a basis for further inquiry.

**Descriptive Assessments**

Descriptive assessment techniques entail direct observations and usually do not involve the manipulation of environmental events. They are used primarily to form hypotheses regarding functional properties of problem behaviors by delineating their relationships with physical, social, or biological variables.

Two of the most used descriptive techniques are the antecedent-behavior-consequence record (ABC; Bijou, Peterson, & Ault, 1968) and scatter plot (Touchette, MacDonald, & Langer, 1985). In the ABC assessment, the observer records what happened immediately before, during, and after the occurrence of a target behavior as it naturally occurred in the environment. The scatter plot is essentially a two-by-two observation system (day and time of day) where raters note the occurrence of behavior problems. It is a rather molar technique, allowing for the assessment of differential rates of behaviors across time and activities. It is a simple method to use compared to other techniques requiring continuous recording. A more sophisticated descriptive technique is the analysis of conditional probabilities. In this technique, the overall probability of the target behavior is calculated. Deviations from the overall probability are then explored in relation to environmental events.

Descriptive techniques are more time consuming than indirect methods, but have the advantage of being more objective. However, they remain correlational in nature and thus can involve confounded data. Several studies have reported inconsistent results between descriptive and analogue assessments (e.g., Mace & Lalli, 1991).

**Analogue Assessments**

In analogue assessments, contingencies are identified through direct environmental manipulations. Iwata, Dorsey, Slifer, Bauman, and Richman (1982) proposed a method for experimentally assessing variables that may be responsible for maintaining self-injurious behavior. In a nutshell, it entails testing the hypothesized function of the target behavior by examining the differential rates of behaviors in different conditions (i.e., experimental control is demonstrated using a multi-element design). Higher rates in one condition relative to others can confirm which
factors maintain behaviors outside of the experimental setting. Iwata et al.’s (1982) method has been applied to a wide range of behavior problems including aggression, feeding problems, destruction of property, stereotypy, and bizarre speech (e.g., see Iwata, Bailey, Neef, Wacker, Repp, & Shook, 1997).

In spite of its rigor, analogue assessments have drawbacks (Desrochers et al., 1997; Sturmey & Bernstein, 2005). They are time and resource demanding, inappropriate for high or low frequency behaviors, and there is always a possibility that different contingencies maintain a behavior in the natural environment. Brief assessments decrease the threats to ecological validity. It is worth mentioning that in recent years, several procedural variations have examined the utility of brief functional analyses in home, outpatient clinic, and classroom environments (e.g., see Northup & Gulley, 2001; Wacker, Berg, Harding, & Cooper-Brown, 2004).

Assessment of the Environment and Psychosocial Stressors

Psychosocial stressors experienced by persons with MR might precipitate a worsening in their emotional or behavioral well-being and lead to significant deterioration in functioning. It is essential that family members and direct support staff be knowledgeable and vigilant of potential stressors in the life of the individual with MR (Levitas & Gilson, 2001). Eliminating or reducing the presence of stressors in the individual’s environment will often be the first course of action in an intervention aimed at reducing the mental health or behavioral problems (Rush & Frances, 2000).

Owen et al. (2004) reported on the impact of stressors on the mental health of 93 individuals with MR living in a residential hospital setting. They compared the number of experienced negative life events (e.g., death of a significant person, change of staff, onset of medical problems) to ratings on measures of mental health and behavior problems. They reported that the presence of negative life events in the previous year was significantly correlated with increased aggression, destructive behaviors, affective, and neurotic disorders. Lunsky and her colleagues have also reported a strong causal relationship between the onset of mental health problems and social strain (Lunsky & Benson, 2001; Lunsky & Havercamp, 1999).

Rush and Frances (2000, p. 168) reported from their expert consensus process the following psychosocial stressors that might significantly impact an individual’s mental health:

<table>
<thead>
<tr>
<th>Source of Stress</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transitions</td>
<td>Change in residence (planned or not), new school, new job, major life changes (e.g., puberty, achieving majority).</td>
</tr>
<tr>
<td>Interpersonal loss or rejection</td>
<td>Loss of parent/caregiver, loss of friend/roommate, romantic break, being suspended from school/fired from job.</td>
</tr>
<tr>
<td>Environmental</td>
<td>Overcrowding, excessive noise, under-stimulation, disorganization, unsatisfactory privacy in shared housing, school/work related stress.</td>
</tr>
<tr>
<td>Social strain</td>
<td>Lack of support from family/friends/partner, destabilizing visits/phone calls/letters, neglect, hostility, abuse.</td>
</tr>
<tr>
<td>Illness or disability</td>
<td>Chronic medical or psychiatric illness, serious acute illness,</td>
</tr>
</tbody>
</table>
sensory deficits, difficulty with mobility, seizure disorder.

<table>
<thead>
<tr>
<th>Stigmatization because of MR</th>
<th>Taunts, teasing, bullying, excluded, exploited.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frustration</td>
<td>Due to an inability to communicate needs and wishes, due to a lack of choices (i.e., work, home, friends, leisure), because of realization of disability.</td>
</tr>
</tbody>
</table>

**Behavioral Treatment of Mental Health and Behavior Problems**

Behavioral interventions have played a prominent role in the habilitation of persons with developmental disabilities since the 1960's. Prior to the application of behavioral techniques, individuals with developmental disabilities were often placed in institutions where they received custodial care and psychotropic drugs to manage disruptive behavior. Behavioral techniques improved daily living skills and reduced the maladaptive behavior of individuals of all ages and all levels of intellectual functioning (Matson, 1990). The results of behavioral interventions generated a positive outlook among professionals regarding the potential of individuals with developmental disabilities to learn new behaviors and to become more independent.

Positive Behavior Support (PBS) is an applied science that uses behavioral methods to expand an individual’s behavior repertoire and systems change methods to redesign an individual’s living environment in order to enhance quality of life and to minimize problem behavior (Carr et al., 2002). PBS integrates behavioral science with person-centered philosophy by emphasizing the importance of coordinating with stakeholders and professionals, by promoting the value of proactive skill-building to prevent the recurrence of problem behavior, and by incorporating strategies that are relevant to naturalistic, community-based settings (Carr et al., 2002; Lucyshyn, Dunlap, & Albin, 2002). The approach reflects a general trend in the social sciences away from a focus on pathology to a positive model that stresses personal competence and environmental integrity (Carr et al., 2002). An analysis of published research on PBS concluded that the approach is widely applicable to people with serious problem behavior and that the field is growing rapidly, especially in the use of assessment and interventions focused on correcting environmental deficiencies. The authors found that PBS was effective in reducing behavior in one-half to two-thirds of the cases and that success rates nearly doubled when the intervention was based on a prior functional assessment (Carr et al., 1999).

Several assumptions are made in adopting a behavioral approach to assessment and intervention. Most importantly, it is assumed that behavior is primarily affected by the conditions existing in the person’s environment, rather than by intra-psychic dynamics. The focus is on current behavior and specific behavior-environment interactions. Through these interactions, the individual learns how his or her behavior affects the environment, including the behavior of others such as parents, teachers, and staff. The goal of behavioral intervention is to change (either increase or

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decrease) one or more specific behaviors. For example, the goal may be to decrease hitting or to increase social skills.

The hallmarks of a behavioral approach to intervention are an operational definition of the target behavior, behavior analysis, and data collection as an ongoing part of assessment and intervention. Essential elements in the analysis of behavior are defining the antecedent conditions and the consequences of the behavior as well as the setting or context in which the behavior occurs. Behavioral interventions focus on systematically changing one or more of these elements. Treatment goals and specific strategies are described in detail in a behavior plan. Once the plan is implemented, data continue to be recorded on the occurrence of the target behavior and the use of the interventions, which indicate the effectiveness of the behavior plan. The plan is modified, when appropriate, to achieve the desired effect on the target behavior.

Please see Appendix B, Statement on the Right to Effective Behavioral Treatment.
Please see Appendix E, Writing an Effective Behavior Support Plan

The Critical Role of Family, Teachers, and Staff Members in Effective Behavior Therapy

The effectiveness of behavioral interventions depends in large part on the implementation by others, including family members and/or support staff (Lucyshyn, Dunlap, & Albin, 2002). Behavioral interventions may be carried out by parents, teachers, staff, peers, or the individual himself or herself. In many cases, the parents, teachers, or staff members are asked to change their behavior because such a change is expected to change the target individual's behavior. To be effective, the behavior plan must be carried out consistently. For this reason, implementation often involves training several caregivers in the details of the intervention (Reid & Green, 1990). In one study, parents were trained to identify and define problem behaviors, conduct a functional assessment, and design appropriate interventions (McNeill, Watson, Hennington, & Meeks, 2002).

The importance of involving family members to participate in behavioral interventions was highlighted in the publication Expert Consensus Guidelines Series: Treatment of Psychiatric and Behavioral Problems in Mental Retardation (Rush & Frances, 2000). Experts were asked to recommend psychosocial treatments for a variety of psychiatric disorders and behavior problems. A striking finding was that for every diagnostic condition and problem behavior, regardless of the severity of the problem or the level of the mental retardation, the experts consistently recommended client and/or family education and behavioral training as first-line treatments. As defined in this report published by the American Association on Mental Retardation, client and/or family education involves helping clients and/or families understand more about behavioral and psychiatric problems and how to manage them.

Importance of a Clinical Team Approach to Treatment

The coordination of behavioral interventions with other approaches to treatment is necessary. Psychiatric and behavioral interventions when coordinated with one another can maximize treatment outcomes. Evaluating the single and joint effects of these different treatments is a complex task that requires multidisciplinary cooperation.
In ongoing treatment, it is important for the behaviorist to coordinate with other health professionals providing services to the client. Individuals with mental retardation and co-occurring mental health or behavioral problems present a complex clinical picture. It is not unusual for individuals with developmental disabilities to have seizure disorders and other chronic health conditions (Havercamp, Scandlin, & Roth, 2004; Hayden & Kim, 2002). Consideration must be given to biological influences on the individual's behavior, as well as the person's skills and needs, and their physical and social environment (Gardner, Graeber, & Cole, 1996). The complexity of the clinical picture necessitates coordination among treating clinicians. A team approach is recommended where each professional providing services to the individual contributes to the team (American Academy of Child and Adolescent Psychiatry, 1999; Esbensen & Benson, 2003; Griffiths & Nugent, 1998; Kuhn & Matson, 2004).

**Behavioral Techniques**

- **Functional Communication Training**

  Problem behavior may be considered a form of communication (Carr & Durand, 1985). For example, if an individual's self-injury is maintained by attention from others (positive reinforcement), the self-injury can be interpreted as a request for attention. The purpose of functional assessment is to determine the function that the behavior serves for the individual. In functional communication training, an appropriate communication behavior that is tailored to the function of the problem behavior is taught as a substitute for the problem behavior. For example, if it is determined that the function of Jenny’s problem behavior is attention, she can be taught a more appropriate means of obtaining attention (communication training). If her misbehavior is then consistently ignored (extinction), Jenny will learn that the only way to get attention is to ask for it appropriately. We would expect her problem behavior to be replaced by the communicative alternative. Appropriate communication is more likely to generalize to new environments and to maintain for long periods of time (Bailey, McComas, Benavides, & Lovascz, 2002; Durand, 1999; Durand & Carr, 1992).

  Several factors have been identified to contribute to the success of functional communication training (Durand & Merges, 2001). First, the alternative communication behavior should match the function of the problem behavior. If the function of the problem behavior is determined to be escape from demands, then the alternative communication should also achieve that outcome. Second, the communication alternative should be a more efficient response than the problem behavior. To be more efficient, it will require less effort to reliably obtain the reinforcer and with no greater delay than the problem behavior. If communicating “I need help” does not reliably and efficiently lead to the desired assistance, then the problem behavior is likely to persist. Third, the communication alternative should be acceptable and recognizable by others. Individuals in the environment need to be able to understand the communication and to respond to it consistently.
Comprehensive multi-modal treatment packages that have proven most effective include functional communication training, choice making, and building tolerance for delay of reinforcement as well as biological or medical treatments (Carr & Carlson, 1993; Gardner & Graeber, 1993; Herzroni & Roth, 2003; Steed, Bigelow, Huynen, & Lutzker, 1995).

- **Reinforcement**

  A reinforcer is an event that increases the probability that the response that directly precedes it will occur again (Singh et al., 1996). For example, getting paid for walking the neighbor’s dog increases the probability that one will agree to walk that dog in the future. This is an example of positive reinforcement, where something is added following the target behavior that increases the probability that the behavior will occur again. In negative reinforcement, the occurrence of a behavior is followed by the removal of an aversive stimulus or a decrease in the intensity of a stimulus and results in a strengthening of the behavior (Miltenberger, 2001). When asking for a break is followed by cessation of work demands, for example, the tantrumming behavior may be negatively reinforced. The reinforcing value of an event varies from individual to individual and from time to time and therefore must be established empirically (Singh et al., 1996).

- **Preference Assessment**

  Determining what will function as a reinforcer for a given individual can be a difficult task, particularly if the person has difficulty making his/her preferences known (Ivancic & Bailey, 1996). A paired stimulus choice assessment procedure has been used to identify preferences for various stimuli among individuals with severe and profound mental retardation (Fisher, Piazza, Bowman, & Amari, 1996; Piazza, Fisher, Hagopian, Bowman, & Toole, 1996). Stimuli are either placed in view of the client or are demonstrated by the therapist (for example, hand clapping). Each stimulus in the assessment is paired with every other stimulus and approach responses to the stimuli are noted. An approach response is interpreted as evidence of a preference. The choice assessment procedure was found to be an effective way of predicting the relative reinforcing value of various stimuli for individuals with severe to profound disabilities (Lavie & Sturmey, 2002; Sturmey, Lee, Reyer, & Robek, 2003). Recently, Sturmey and colleagues developed the Choice Assessment Scale, a rating instrument to identify potential reinforcers for people with severe and profound mental retardation (Sturmey, Matson, & Lott, 2003).

- **Motivation System**

  A motivation system or token reinforcement system is often used as one component of a behavior support program. A token reinforcer is like money; it is something that can be exchanged for a desired object or activity at some future time. There are several advantages to using a token reinforcement system. Tokens are tangible and concrete; a person knows instantly when reinforcement is received. Tokens can be given immediately after the desired behavior, even though the back-up reinforcer may be delivered at a much later time. Tokens allow the reinforcement to be broken into small segments; several tokens may be required to earn a valued reinforcer. Examples of commonly used tokens include poker chips, milk bottle tops, points on a card, and stickers.
Matson (1982a) provided behavioral treatment involving a combination of techniques to three men with mild mental retardation who displayed repetitive clothes checking or body checking. A procedure was instituted in which reinforcement was given for not performing the checking behavior while the men completed work tasks. Tokens were provided for each minute out of 30 that the behavior did not occur. The tokens could be exchanged later for snacks. This procedure successfully reduced the checking behavior.

○ **Behavior Shaping**

If the desired response is not in the person's repertoire, it cannot be reinforced. One procedure that can be used to teach a new behavior is shaping. Shaping of behavior occurs when a reinforcer is provided for behavior that is increasingly similar to the target desired behavior. Reinforcement is then presented differentially for responses that more closely match the desired behavior, or successive approximations, until the desired response is performed. Once the desired response occurs, it alone is reinforced to the exclusion of lesser approximations (Martin & Pear, 2003).

○ **Extinction**

When a previously reinforced behavior is no longer reinforced, a process of extinction occurs in which the behavior reduces in frequency. By design, any reinforcement program also involves extinction because certain behaviors are reinforced while others are not (Singh et al., 1996). Lovaas and Simmons (1969) found that for some children, self-injurious behavior decreased from more than 2,000 acts during the first session to no self-injurious acts in the 10th session once all sources of social reinforcement were removed. Magee and Ellis (2000) described an extinction burst where new target behaviors emerged as extinction was introduced sequentially across several problem behaviors. All target behaviors eventually decreased once extinction was applied systematically across all behaviors.

○ **Self-management**

Often, behavior plans incorporate some aspect of self-management. With a self-management program, the individual is taught three skills: self-monitoring, self-evaluation and self-reinforcement. The individual observes his or her own behavior and records instances of target behaviors and desirable behaviors. The individual delivers reinforcement to him- or herself following self-evaluation of desirable behavior, but not after target behaviors (Carr et al., 1999). Video technology has proven to be a valuable tool in self-modeling and video feedback (Coyle & Cole, 2004; Embregts, 2003). Embregts (2003) used video feedback and self-management procedures to increase desired behavior in children with mental retardation and their staff members. Participants were videotaped during lunch and then shown segments of the tape and asked whether the observed behavior was appropriate or inappropriate. The students earned tokens for the identification of appropriate and inappropriate behaviors and were praised for appropriate behavior. Staff members were praised and provided corrective feedback based on their videotaped responses to the student’s behavior. Rates of inappropriate target behaviors decreased for students with externalizing behavior problems and appropriate target behaviors increased for students with internalizing behavior problems. Both staff and students rated the video feedback and self-
management strategies as very effective and pleasant. In another study, self-management procedures increased the rates of academically engaged behavior and work completion in a 10-year old girl with Down syndrome and mild mental retardation in her fourth-grade classroom (Brooks, Todd, Tofflemoyer, & Horner, 2003).

- **Punishment**

  Please note that, according to North Carolina statutes (10A NCAC 27E.0104), the use of restrictive procedures including seclusion, restraint, isolation time-out, and protective devices for behavioral control are limited to 1) emergency situations, in order to terminate a behavior or action in which a client is in imminent danger of abuse or injury to self or other persons or when property damage is occurring that poses imminent risk of danger of injury or harm to self or others; or 2) as a planned measure of therapeutic treatment.

  Punishment is a procedure in which the target behavior is followed by a consequence that decreases its future probability of occurrence. There are several behavioral procedures that can function as punishment including removal of reinforcement, verbal reprimands, withdrawal of privileges, and isolating the person from a reinforcing environment. Punishment procedures are to be used as a last resort, after reinforcement-only procedures are tried and found to be inadequate or when the problem behavior presents a danger to self or others. When punishment is used to decrease problem behaviors, it is critical to use reinforcement procedures at the same time to develop appropriate behaviors, often functionally-equivalent communicative replacement behavior. In a meta-analysis of behavioral interventions, Scotti, Evans, Meyer, and Walker (1991) concluded that while punishment procedures were effective in suppressing maladaptive behavior, their effects were enhanced when combined with reinforcement procedures.

- **Response Cost**

  Response cost procedures are frequently and successfully used to decrease rates of behavior. Response cost procedures do not involve the addition of stimuli which cause pain, illness, cold, or some other aversive condition. Rather, they involve the contingent removal of a preferred stimulus. Time-out and overcorrection are forms of response cost. The addition of response cost to a reinforcement procedure resulted in a significant decrease in inappropriate vocalizations in an adult with autism (Falcomata, Roane, Hovanetz, Kettering, & Keeney, 2004). In another study, the use of a token economy with a response cost procedure successfully treated excessive inappropriate social behavior in an adult with moderate mental retardation (LeBlanc, Hagopian, & Maglieri, 2000).

- **Overcorrection**

  Overcorrection involves either repeatedly restoring a setting (or individual) to its previous state before the occurrence of an undesirable behavior or the positive practice of behavior that is incompatible with the undesired response (Singh et al., 1996). For example, an individual who overturns a chair in a lounge area could be first manually guided and then instructed in the replacement and arrangement of all the chairs in the room. Cole, Montgomery, Wilson, and Milan
(2000) used positive practice overcorrection to reduce stereotypic hand behavior in adults with severe to profound mental retardation.

- **Time-Out**

  Time-out from positive reinforcement involves interrupting the reinforcement obtained by the individual contingent on undesirable behavior. Time-out can be exclusionary, in which the individual is removed from the setting for a period of time, or it can be non-exclusionary, in which the individual remains in the setting, but potential reinforcers are removed (Singh et al., 1996). The absence of the problem behavior is usually required to reinstate the previous reinforcing conditions. A combination of differential reinforcement and time-out has proven effective in treating a variety of behavior problems in children (Alberto, Heflin, & Andrews, 2002; O’Conner, Sorenson-Burnworth, Rush, & Eidman, 2003) and adults with mental retardation (Toole, Bowman, Thomason, Hagopian, & Rush, 2003).

**Contextual Factors**

Behavior is not emitted in a vacuum. A large research literature has documented that the occurrence of problem behavior is a function of both antecedents, such as task demands, and consequences, such as attention, escape from demands, and tangibles. This understanding is the basis of functional assessment. A behavior is under stimulus control when its occurrence can be predicted by knowing whether or not a stimulus (a particular person, for example) is present in the environment (Cipani, 1990). When a behavior is under stimulus control, there is a high probability that it will occur given that the stimulus is present.

In recent years, researchers have begun to explore the role of broader contextual influences on problem behavior. These broader influences, or setting events, affect the impact of antecedents on behavior. Setting events may include physical, social, and physiological factors including mental health status (Baker, Blumberg, Freeman & Wieseler, 2002). Carr et al. (2003) found that staff ratings of bad mood strongly predicted that problem behavior would occur in the context of task demands, whereas a rating of good mood strongly predicted that problem behavior would not occur in the same context. They further demonstrated that a mood induction procedure was effective in increasing the completed task steps following intervention. In addition, the occurrence of problem behavior fell to a near zero level after mood induction. Recently, a contextual assessment inventory was developed to identify contextual variables relevant to problem behavior in individuals with developmental disabilities (McAtee, Carr & Schulte, 2004).

**Specific Examples of Behavioral Interventions**

*Interpersonal Skills*

Social skills deficits are characteristic of people with mental retardation due to their adaptive behavior deficits. Interpersonal skills are also of particular concern because of the association
between poor social skills and psychopathology (Benson, Reiss, Smith, & Laman, 1985). Social skills training is often one component of a multifaceted treatment package. A number of behaviorally-based interventions that focus on improving social skills of persons with mental retardation have been developed. Two notable programs for improving social skills of adults with mental retardation are Stacking the Deck (Foxx & McMorrow, 1983) and Home-of-Your-Own Cooperative Living Skills (Tassé, Havercamp, & Reiss, 1997). Additional interventions are described in Benson and Valenti-Hein (2001).

Stacking the Deck (Foxx & McMorrow, 1983) is designed to be used with a board game. Players move their game pieces around the board by correctly answering questions of a social skills nature. The playing cards are organized by skill areas such as compliments, social interaction, politeness, criticism, social confrontation, and question and answers.

The Home-Of-Your-Own Cooperative Living Training Program (Tassé, Havercamp, & Reiss, 1997) is a curriculum that incorporates behavioral techniques to improve skills required for sharing a residence. The skills are broadly defined as those that facilitate living and getting along with others and include borrowing and lending, sharing chores, respecting privacy, and resolving conflicts. The curriculum is designed to be used in groups of adults with mental retardation during 10, one-hour sessions. The behavioral techniques used in each session include: instruction, discussion, modeling, role-playing (participant modeling), and feedback (positive reinforcement). The authors field-tested and revised the curriculum over the course of two years based on their experience with fifteen different groups of over 100 individuals who had mental retardation or developmental disabilities.

**Relaxation Training**

Relaxation training is a group of techniques that reduce anxiety and other types of emotional arousal (Smith, 1985). The methods range from progressive muscle relaxation in which several muscle groups are individually tensed and relaxed (Bernstein & Borkovec, 1973) to imagery-based procedures and meditation. For each, the goal is to reduce tension and to produce a calm state in body and/or in mind. Relaxation training can be a primary intervention used to reduce general anxiety levels or it can be one part of a treatment "package." In systematic desensitization, a fearful client trained in relaxation skills imagines, or experiences in vivo, a series of anxiety provoking situations starting with the least anxiety-provoking (Ollendick & Cerny, 1981). In anger management training (Benson, 1994), relaxation training is included to reduce arousal associated with anger-provoking situations.

Among the modifications used to enhance relaxation training for persons with mental retardation are the use of simplified language, physical prompts and guidance, behavior shaping of the response, biofeedback, and positive reinforcement for practice (Harvey, 1979). The addition of modeling and physical guidance to relaxation training helps individuals functioning in the severe range of mental retardation discriminate between tense and relaxed states (Lindsay, Baty, Michie, & Richardson, 1989). Adapting relaxation training procedures for individuals with special needs is the subject of a manual (Cautela & Grodin, 1979) and a videotape (Grodin, Cautela, & Grodin, 1989).
Behavioral Relaxation Training (BRT; Poppen, 1998) was adapted for persons with developmental disabilities. It has the advantage of being easy to learn and easily implemented in everyday situations. BRT differs from progressive muscle relaxation training in that BRT does not require muscle contraction. Some persons with developmental disabilities may be confused and have difficulty discriminating between tensed and relaxed states in progressive muscle relaxation. In addition, muscle contraction may be contraindicated for problems related to muscle tension such as tension headache. Another advantage of BRT is that it is easy for both trainer and trainee to monitor acquisition of target behavior. This avoids what is known as “the problem of privacy” in which the trainer attempts to teach discriminations of events to which he or she has no direct access. For example, it is impossible for the trainer to verify the trainee’s thoughts during visual imagery or meditation exercises.

BRT emphasizes motoric behavior. The trainee is instructed to observe his or her overt body postures as well as the covert proprioceptive sensations and other feelings of relaxation that accompany them. Ten relaxed body positions are taught. Verbal definitions and “labels” of relaxed postures are provided, and these may be covertly echoed by the trainee and used during practice on his or her own. Visceral behavior, such as slowed breathing, and diaphragmatic breathing instruction also may be included in this training. Behavioral relaxation skills are quickly acquired (Lindsay & Baty, 1989) and effective in treating chronic headaches (Michultka, Poppen, & Blanchard, 1988) improving performance on laboratory learning tasks (Lindsay & Morrison, 1996), improving concentration and decreasing rated anxiety, in adults with severe and profound mental retardation (Lindsay, Fee, Michie, & Hcap, 1994; Lindsay, Baty, Michie, & Richardson, 1989).

Behavioral Treatment of Psychiatric Disorders

Anxiety

Anxiety disorders have been successfully treated in persons with developmental disabilities using behavioral or cognitive-behavioral approaches to therapy and often in combination with psychotropic medication.

Specific phobia

Reports of successful treatment of specific phobia have included graduated exposure procedure, relaxation training, modeling, non-contingent access to distracting and preferred items, and reinforcement procedures (Hagopian, Crockett, & Keeney, 2001; Newman & Adams, 2004). Exposure to the feared stimuli while preventing avoidant behavior and aversive events is believed to result in both extinction of negatively reinforced avoidant behavior as well as extinction of the association between the feared stimuli and the aversive event.

Post-traumatic Stress Disorder

Post-traumatic stress disorder (PTSD) is an anxiety disorder that may occur following an event that presents an actual or perceived threat of injury. The person’s emotional response to the event includes intense fear; there are possible flashbacks to the event, as well as avoidance, sleep
disturbances and other symptoms. People with mental retardation are vulnerable to PTSD due to
the documented high rate of violence and abuse (Sobsey, 1994). An effective intervention for PTSD
involves exposure to the threatening stimuli which allows the fear to extinguish. Lemmon and
Mizes (2002) reported the use of exposure therapy with a woman with mild mental retardation and
PTSD following sexual assaults. The intervention included imaginal exposure to a hierarchy of
anxiety-arousing cues that were associated with traumatic events and later in-vivo exposure to
trauma-related cues, such as the environments in which the assaults occurred. Following treatment,
psychological distress and physiological reactivity were significantly reduced.

For individuals with mental retardation who have difficulty expressing themselves, an act of
refusal is one way to communicate. Some instances in which individuals are considered
noncompliant could be due to anxiety or fear concerning the activity (Benson, 1990b). When
noncompliance seems associated with a particular type of activity, rather than a general pattern of
refusal, further inquiry is in order to determine if the avoidance is anxiety based.

Aggression

Disruptive behavior in persons with mental retardation is frequently defined as including
aggression toward others, self-injury, and property destruction (Thompson & Gray, 1994). This
group of behavior problems is of great concern because of the potential for serious harm as well as
because the behaviors interfere with attention, learning, and social and intellectual development. A
brief discussion of interventions for disruptive behaviors is provided here. Additional information
can be found in Benson and Aman (1999), Murphy (1997) and Gardner (2002).

Operant Model of Aggression

It has long been recognized that destructive behaviors are often learned because they are
reinforced in some way (Carr, 1977; Ferster, 1961). For example, Carr proposed that self-injurious
behavior is learned, operant, and maintained by either positive social reinforcement or by the
termination of an aversive stimulus (negative reinforcement). He also reviewed a self-stimulation
hypothesis which suggests that self-injurious behavior may be a means of providing visual, tactile, or
auditory sensory stimulation (see also Vollmer, 1994). Other researchers recognized the purposeful
nature of other types of problem behavior such as aggression (Sigafoos & Siggers, 1995), property
destruction (Gardner & Cole, 1990), and stereotypy (Rojahn & Sisson, 1990).

Foxx (2003) summarized several case studies in which severe aggressive behavior was
successfully treated with behavioral interventions. Functional analysis was used to identify the
determinants of the behaviors which were often multiple and complex. The comprehensive
intervention programs included punishment procedures, reinforcement, communication training,
increased choice making and other approaches. Significant improvements in behavior were
maintained at long-term follow-up. The author contrasts the temporary restrictiveness and use of
punishment for dangerous behavior in the behavioral intervention to the prior years of ineffective
treatment through restraint, seclusion, and large doses of psychotropic medications.
Anger management training

Anger management training is a self-management approach to dealing with aggressive behavior. The goal of anger management training is to improve the self-control skills of the individual (Novaco, 1975). The cognitive-behavioral intervention was adapted for persons with mild to moderate mental retardation. In an early study, groups of adults participated in a 12-week outpatient group in which the primary intervention was either relaxation training, self-instructional training, problem solving skills training, or a combination of the three interventions (Benson, 1994; Benson, Rice, & Miranti, 1986). The techniques of training included lecture, discussion, modeling, role-playing, feedback, and homework. Benson et al. (1986) reported improvements in supervisor ratings of behavior, self-report, and role-play measures at post-test and follow-up, but no significant difference between the treatment groups. A no-treatment control group was not included in the study.

An anger management group intervention was contrasted with a waiting-list control group by Rose, West, and Clifford (2000). Over a period of two years, groups of 5-9 adults participated in 16 treatment sessions; each participant was accompanied by a care worker. Reductions in self-reported anger and depression were obtained at follow-up evaluations 6 and 12 months later. The inclusion of the care worker was thought to aid the transfer of skills learned in the group to the outside environment and to manage some contextual cues that could be associated with anger arousal.

Substantial progress has been made in applying anger control treatment to offenders with mental retardation who are confined to secure settings. In a publication that consolidated treatment results over a number of years, Lindsay et al. (2004) reported that 40 weekly group sessions were effective in reducing anger self-reports and anger responses during role play performance. The intervention included relaxation, problem solving, and stress inoculation through role play practice. Long-term follow-up revealed a generalization of treatment gains and a reduction in re-offending in comparison to waiting-list controls.

In individual anger control treatment, the intervention can be tailored to the needs of the individual in a greater degree than in a group intervention. Taylor, Novaco, Gillmer, and Thorne (2002) found that 18 sessions of individual anger control treatment was superior to routine care in reducing anger intensity of offenders. In a review of the anger control treatment studies to date, Taylor (2002) concluded that there is still room for improvement in the assessment and treatment of aggression in offenders with intellectual disability. Assessment tools need to be refined and treatment and control groups should be conducted across a range of settings.

Depression

The behavioral treatment of depression in persons with mental retardation has focused on verbal statements and nonverbal behaviors occurring in social interactions (Benson, 1990a). A variety of behavioral techniques have been applied including self-management. Matson, Dettling, and Senatore (1979) worked with a man with borderline to mild mental retardation and a long
history of depression. The intervention included modeling, praise (reinforcement), self-evaluation and self-reinforcement (self-management). The target behaviors were negative self-statements, suicide statements, and participation in activities. In individual training sessions, the man was praised for positive self-statements and he was asked to praise himself as well. If he made a negative self-statement, the therapist modeled an appropriate statement and the man rehearsed the modeled statement. Homework assignments were given which required tallying positive statements and noting participation in activities. Positive statements and participation in activities increased following the treatment. Using a similar intervention, Matson (1982b) reported the treatment of somatic complaints, negative self statements, and grooming in four adults with mental retardation and depression. Following a range of 10 to 35 individual sessions, the four participants improved in verbal and nonverbal behaviors and in self-reported depression.

The psychosocial treatment for depression in the general population has moved toward cognitive-behavioral therapy as the standard. There have been some reports of successful cognitive-behavioral therapy for depression in persons with intellectual disabilities (Lindsay, Howells & Piteaithly, 1993). Following a review of a number of cognitive therapy interventions for persons with intellectual disabilities, Sturmey (2004) concluded that many include both behavioral and cognitive components making it difficult to determine which elements are responsible for the reported improvement.

**Psychosis**

Behavioral techniques have been used to improve the social skills (Stephens, Matson, Westmoreland & Kulpa, 1981) and decrease the inappropriate verbal behavior of individuals diagnosed with psychotic disorders (Wilder, Masuda, O’Connor & Haham, 2001). Dixon, Benedict, and Larson (2001) describe the functional assessment and successful treatment of inappropriate vocalizations (e.g., inappropriate sexual comments, illogical or irrational statements) in a man, “Fernando,” with moderate mental retardation and a psychotic disorder not otherwise specified. The inappropriate verbal behavior was attributed to auditory hallucinations symptomatic of his underlying psychotic disorder. Inappropriate verbal behavior was defined as vocal utterances that were not relevant to the context or were sexually inappropriate, illogical placement of words within a sentence, or “psychotic” statements.

A functional analysis of Fernando’s inappropriate verbal behavior was conducted alternating four conditions (attention, demand, alone, and control) in a multi-element design. During the attention condition, the experimenter responded to Fernando’s inappropriate verbal utterances with 10s of attention. During the demand condition, the experimenter presented Fernando with basic academic tasks. Each occurrence of inappropriate verbal behavior produced 10s of escape from the tasks. During the alone condition, Fernando was in the room alone and observed via a one-way mirror. During the control condition, Fernando had access to his favorite activities (puzzles, markers, and craft supplies). The experimenter delivered non-contingent attention every 30s and provided no consequences for inappropriate behavior. The results of the functional analysis suggested that inappropriate verbal behavior was maintained by attention from others.
The intervention consisted of reinforcement (attention) contingent on appropriate verbal utterances. No attention was provided to Fernando following the emission of an inappropriate verbal statement. The intervention was alternated with a baseline condition where inappropriate behavior produced attention and appropriate verbal behavior was ignored. The treatment was associated with a decrease in the number of inappropriate utterances and a corresponding increase in appropriate utterances. These results were replicated across several contingency reversals, indicating that the treatment was effective in controlling the content of Fernando’s verbal behavior. The successful intervention to reduce inappropriate verbalizations associated with psychosis indicates that when psychiatric symptoms are functionally related to conditions in the environment, that they can be altered through systematic changes in the consequences for the behavior.

Although there are many behavioral interventions that could be incorporated into a behavioral treatment plan, a task force recommended that the selection of interventions proceed by choosing the least restrictive, effective technique from among those available to deal with that particular problem behavior (Van Houten et al., 1988). Further, an analysis of risks and benefits of treatment procedures should be conducted (Axelrod, Spreat, Berry, & Moyer, 1993). See appendix B, Statement on the Right to Effective Behavioral Treatment.

Best Practice Related to Problem Behaviors

- Comprehensive (multi-disciplinary) clinical assessment including a thorough medical assessment to address health problems including mental health problems that may contribute to problem behaviors
- Functional assessment of problem behavior
- Identify strategies to prevent occurrence of problem behavior with a focus on reducing sources of stress in the environment
- Identify efficient (known or easily learned) and effective (recognized by the caregivers) form of communication for the consumer to use to obtain the desired response (functional communication training)
- Design & implement a positive behavior support plan using the least restrictive effective techniques. Punishment and any type of seclusion, restraint, or medication for problem behavior must be used only as a last resort.
- Design and implement crisis management plan, if needed
- Train caregivers to carry out the plan consistently
- Train caregivers toward a behavioral understanding of problem behavior, mental health problems, and on positive behavior support techniques
- Behavioral data is needed to monitor and fine tune the plan.

SPECIAL NOTE: For treatment of psychiatric disorders in individuals with developmental disabilities, please refer to the Mental Health Treatment Protocols for the appropriate disorder. For those disorders that may be reasonably treated with psychotherapy, the cognitive, communication, and relational skills of the individual with a developmental disability must be assessed, with the goal of determining whether or not psychotherapy is likely to be the most effective treatment approach
and what modifications/supports may be necessary to achieve success. For example, use of a sign language interpreter in case of deafness or inability to speak; or organizing therapy around concrete and specific problem solving techniques in persons with mild to moderate cognitive problems might be appropriate. In most cases where psychotherapy is being considered for a person with developmental disabilities, clinical consultation/specialist review would be appropriate to determine if psychotherapy is likely to be an effective treatment.


## Crisis Management

*Crisis means deterioration in the medical, psychological, or physical condition of an individual, posing imminent risk to the health or safety of the individual or others.*

The best way to handle a crisis is to prevent it from occurring in the first place. Crisis management plans must address three levels of prevention. Primary prevention includes activities, strategies, and supports that PREVENT the crisis from occurring altogether. Secondary prevention includes activities, strategies, and supports that ARREST potential crises from escalating. Tertiary prevention includes activities, strategies, and supports that REPAIR damage that result from a crisis.

The key to prevention is an effective positive behavior support plan (see section on Behavioral Treatment for more information). Positive behavior support involves the following considerations:

1. reduce general stressors in the individual’s life (e.g., physical illness, loneliness, boredom)
2. remove antecedents (triggers) and incidental reinforcers
3. increase choice and structure
4. teach prosocial skills as adaptive replacements of problem behavior
5. reward successful self-management

### Stressors that may trigger behavior problems or crises

<table>
<thead>
<tr>
<th>Type of Stressor</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transition</td>
<td>Change in residence (planned or not), new school, new job, major life changes (e.g., puberty, achieving majority)</td>
</tr>
<tr>
<td>Interpersonal loss or rejection</td>
<td>Loss of parent/caregiver, loss of friend/roommate, romantic break, being suspended from school or fired from job</td>
</tr>
<tr>
<td>Environmental</td>
<td>Overcrowding, excessive noise, under-stimulation, disorganization, unsatisfactory privacy in shared housing, school/work related stress</td>
</tr>
<tr>
<td>Parenting and social support</td>
<td>Lack of support from family/friends/partner, destabilizing visits/phone calls/letters/emails, neglect, hostility, abuse</td>
</tr>
<tr>
<td>Illness or disability</td>
<td>Chronic medical or psychiatric illness, serious acute illness,</td>
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</table>
A crisis plan is an important tool to support the treatment team in managing emergency situations. While it may be part of a behavior plan, it does not replace the behavior or treatment plan. *A crisis plan must always be person-centered.*

**Essential Elements in a crisis plan:**

1. name and contact information of legal guardian
2. current diagnoses
3. current medications and name and contact information for treating physician
4. known allergies (e.g., medications, base elements, etc)
5. specific behaviors that are focus (necessitate) crisis plan and known antecedents/triggers and early warning signs of emotional upset
6. Procedures to follow and avoid- to prevent crisis (step-by-step instructions for staff/family)
7. description of crisis stabilization and support strategies (step-by-step instructions)
8. Listing of (1) person to contact and (2) critical phone numbers
9. client specific guidelines- rather than generic planning
10. Procedure to access services/diversion
Section V

Practice Guidelines in Habilitation Assessment
Practice Guidelines Related to Assessment of Social Skills

Assessment of social skills, as reported in the literature, occurs through validated instruments (Castles & Glass, 1985; Clare & Clements, 1990; Wildman et al., 1986; Valenti-Hein, et al., 1994) direct observation (Wildman, et al., 1994) and the measurement of social validity (Chadsey-Rusch, 1992; Wildman, et al., 1986). Wildman, et al., (1986) has demonstrated that improved social skills by consumers with developmental disabilities resulted in non-handicapped and community individuals rating those consumers as having better conversational skills. They also thought the subjects would fit into the community better and less likely to be identified as mentally retarded. Chadsey-Rusch (1992) suggested the measurement of social skills along the following dimensions: Measuring the perceptions of others, measuring the goals and perceptions of the target individual, and measuring the performance of social behaviors in natural contexts. This includes measuring contextual variables, measuring the topography of the response (which means observing what actually occurs in a natural situation), and measuring the consequences of the social behaviors. Langone, et al., 1995 suggest that the social skills demands placed on the learner be evaluated. Assessment should include the following areas:

- Evaluation of skills and related deficits in the Consumer's natural environment(s)
  - Measure contextual variables (this includes issues specific to a given situation).
  - Measure topography of consumer behavior (including vocalizations, facial expressions, and gestures).
  - Measure consequences of both inappropriate social behavior and appropriate social behavior. Consider long-term variables like isolation, potential loss of jobs, no support from others, potential for increased abuse, and poor emotional adjustment. Also, consider immediate consequences that may have the effect of reinforcing.
  - Analyze the types of demands likely to be placed on the consumer in each desired or required environment. For example, the senior center will have different demands than a work setting.
  - To the degree that it is possible, identify whether deficits are cognitive, physical, or behavioral.

- Include perception of other people's beliefs about which skills are most important to address. "Other people" to be defined by who the Consumer chooses to participate within the plan.

- Consider the use of validated measurement instruments to determine change in social functioning over time.

Practice Guidelines Related to Assessment of Self-Care Skills

All adults with developmental disabilities must be assessed for self-care skills and ability to perform them at the appropriate times and in appropriate situations. Efforts must be made to determine if observed problems are cognitive, physical, and/or behavioral in nature. Self-care activities should be assessed under conditions where natural cues that would trigger these activities are present. Many adults with developmental disabilities may have learned to perform self-care skills in day programs or other settings that are not the normal place that these activities take place. For
example, the consumer could be observed getting up in the morning to see if, and how well, morning routines are completed without any outside help, prompts or supervision. Care takers and significant others are important sources of assessment information regarding self-care. Thorough assessment of self-care is essential as this is often used to determine needs for supports and type of residential setting. Assessment should cover the following areas:

- All individuals suspected of having physical or neurological difficulties that can affect self-care skills should be assessed by appropriate licensed health care providers. Intensive adaptive training would be inappropriate if the person is physically unable to perform the activity.
- Assessment must address sensory and physical deficits that may interfere with self-care. These can often be supported with environmental structure and adaptive devices. An occupational therapy assessment may be necessary to determine need for adaptive devices.
- For cognitive deficits, information about each individual's learning style can help guide supportive measures (i.e., some people respond better to visual cues, or repetition, or a chart).
- Behavioral barriers to performing self-care should be identified if the consumer appears to have the cognitive and physical ability to perform self-care. Evaluating antecedents and consequences, as variables must occur to determine possible reasons why self-care is not occurring in an apparently able individual. Possible antecedent variables that may relate to refusal to perform self-care are such things as the way the request is being delivered, changes in normal scheduling, distracting influences in the environment, etc. Possible consequences of refusals that may serve to reinforce refusal to perform self-care include the attention the consumer receives if the staff person must actually provide the care or must intensively address non-compliance or behaving inappropriately following a request to avoid the self-care task. On the other hand, some type of planned reinforcement (edible or otherwise) following adequate performance can serve to increase such performance in the future.

**Practice Guidelines Related to Assessment of Home Living Skills**

Assessment must be comprehensive when considering residential options for individuals with developmental disabilities. Data collected relevant to all functional domains should be reviewed. The following are issues and areas that should be evaluated:

- Consumer and family preference must be determined. This may require some effort to support choice making skills for the consumer.
- Age and life stage should be considered to enhance age appropriate services. For example, an older adolescent or young adult may benefit from intensive community use and home living skills training, whereas an older adult may choose more of a supported approach.
- Basic abilities and adaptive behaviors must be assessed at the appropriate level. Supervision and/or supports can be provided.
- Physical disabilities should be noted to provide the best match between consumer and environment. Some individuals may need barrier free environments or other adaptive modifications.
Level of support necessary to ensure that basic and other needs are met is often more useful for determining appropriate placement, than are specific deficits.

Available residential options should be identified. If the person is currently in a desired residence (i.e. family home or own apartment), assess the environment to determine if supports and/or modifications are needed.

Assessment determines if supports need to be continuous or intermittent. For example, an individual may be doing fine, as long as a relative is in residence with him, but may need supports if the relative needs to be away. It is preferable to make this determination during the assessment process rather than waiting for a crisis to occur.

A Residential level of care assessment instrument such as the Support Intensity Scale helps establish the level of support needed across life domains. This information should inform the planning for home living programming and supports. The tool should be completed by the initial assessor, caregivers, the consumer if possible, and interested family. It should be re-done periodically to reflect progress and the consumer's desires and needs for having supports.

Practice Guidelines Related to Assessment of Community Use

Person-Centered Planning is an ideal way to determine how much a person needs to or wants to access the community. Alternative opportunities should be presented so there is a greater awareness of choice and opportunity. One of the greatest challenges we have is education regarding options. Assessment of an individual's dreams will be more valid, as more individuals with developmental disabilities become aware of what is open to them. The functional domain of self-determination addresses this issue in more detail. As with the other functional domains, assessment must determine the bases for problems. It is important to differentiate, as much as possible, whether problems in attaining desired community use are related to cognitive problems, physical problems (including health issues), challenging behavior, or some combination of these. Appropriate professionals, such as nurses, occupational therapists, speech therapists, and psychologists should contribute to assessment of community use as necessary. As many factors contributing to community use or lack thereof are found in assessment of other domains, the essential areas that need assessment are as follows:

- Determination of what community resources the individual needs and wishes to use
- Actual report or observation (from the individual and/or significant others and caregivers) of current community use
- Specific reasons for non use of desired or needed resources
- Actual resources available in the individual's community
- Determination of whether the individual has opportunities to make valid choices
- Assessment must further consider life stage relative to the above issues. Transition from school to work or from work to retirement may necessitate that different community resources be considered or introduced.
- Specific need areas to assess include:
  - Needs and Desires
  - Family/Significant Other/Caregiver Input
  - Strengths and Abilities
Practice Guidelines in DD

- Natural Supports (family, neighbors, volunteers)
  Paid staff including caregivers and persons in the community that offer services as a community function
- Community Resources
- Physical Health and Endurance
- Community Safety Skills
- Public Transportation Skills
- Social Skills
- Money Management Skills

Practice Guidelines Related to Assessment of Functional Academics

Assessment of functional academic ability must focus more on what the individual actually needs to be able to do rather than what they can produce in a testing situation. Further, academic performance deficits may be cognitive or may have roots in physical or sensory deficits. Obviously, it would be important to differentiate these. The person AND the demands stemming from the environment must both be evaluated in the context of the individual's life goals and desires as determined through Person-Centered Planning. Assessment may include the following:

- Testing aimed at evaluating IQ and academic skills if available, may be reviewed or may be conducted if there are compelling reasons to do so. Such test results may assist in learning about the person's abilities.
- Achievement and aptitude tests may also be utilized to determine adaptive functioning in the academic environment. These are usually performed by the school psychologist, but may be indicated when considering supported employment.
- Specific cognitive deficits that interfere with academic style learning should be identified if possible. For example, short-term memory deficits, inability to learn effectively from auditory cues, or a number related learning disability would require different training or teaching approaches.
- Needs for academic performance should be identified based on the person's environment and goals. For example, if the person wants to use public transportation, they may need to be able to recognize certain signs on buses.
- The individual's desire to learn any specific academic skills should be assessed separately from the actual skills they may need, as there may be supports that can be used instead. The individual should be assessed in the actual environment or setting in which the skills need to be used. Just because the person cannot read an offered piece of text, does not mean that they cannot recognize and read a sign posted over their work area.
- Physical and sensory deficits that may interfere with academic performance should be assessed, as well as any adaptations/accommodations for these that have been tried.

Practice Guidelines Related to Assessment of Employment Needs

A complete vocational assessment is recommended to adequately evaluate the future employee’s interests, abilities, previous work experience, available supports and needs. This should be considered an essential process related to transition from school to work and, therefore, will involve
coordination between both services. As with many other functional domains, deficits and problems with work may be cognitive, physical, or behavioral in nature, or a combination of these. The assessment must contain items aimed at differentiating causes requiring different types of supports and/or interventions. The assessment should be completed with the individual and support persons (family, friends, caregivers). Consideration for the individual's ability to communicate accurate information is critical. Support persons may be necessary to obtain complete information. Assessment should include at least the following:

- Individual preference or interests in work related activities
- Individual deficits that may require supports, clearly defining cognitive, physical and/or behavioral deficits
- Work history, if present
- Knowledge and abilities related to obtaining work, such as interviewing skills
- Psychological assessment to specify cognitive deficits, behavioral assessment to specify behavior challenges, and/or occupational therapy assessment to specify physical problems that might be supported by adaptive devices may be necessary.
- Health must be assessed to ensure stamina, activity tolerance, and other health issues are consistent with proposed work.
- Aptitudes for specific types of work; some aptitude testing may be indicated.
- Trial experiences with a variety of working situations and tasks to enable the Consumer to make choices based on experienced preferences.

It is already assumed that all consumers will have access to employment services and options if that is their desire. When a vocational service provider has been selected or identified, the first step in the supported employment process is assessment and employment planning. Assessment is NOT done for the purpose of eliminating an individual from vocational services. Assessment seeks to gather and review information from a variety of sources, including the individual, that identify skills, abilities, desires, preferences, levels of current performance and support needs. Assessment of functional abilities should take place in real life settings to ensure that it is ecological and not reliant on simulation. Assessment information should be current; past performance in workshops or day activity settings should NOT be predictors of success or failure in community jobs.

There are many assessment tools available to assist service providers and individuals in employment planning. Whatever assessment technology is chosen, it should be ability focused and provide a "profile" of the individual that identifies both assets and support needs. A "profile" should include the following information:

- Vocational Interests
  - Ideal Employment Scenarios
  - Skills/Abilities/Assets
  - Dreams/Aspirations
  - Environmental Needs
- Employment Quality Considerations
  - Wages/Benefits
  - Potential for Advancement
- Location
- Opportunities and Levels of Inclusion
- Other Factors Identified by the Individual as Important
  - Educational/Work Experience
  - Present Level of Performance with Areas of Support Required
  - Support Systems
  - Support Needs
    - Physical
    - Behavioral
    - Financial
    - Transportation
    - Medical
  - Residential Information
  - Medical Information
    - Medications
    - Seizure Information
    - Restrictions

Person-Centered Planning processes are effective in vocational assessment and employment planning. The information accessed through this process is used to assist the individual in selecting desired employment opportunities and assists the service provider in developing appropriate jobs and identifying the necessary supports for successful employment outcomes.

To assess an individual's functional work skills, abilities, and support needs, the assessment should be in the context of a real work environment and real work demands. Situational assessments can be negotiated with employers or worksites can be identified for the specific purpose of evaluating functional work skills. These situational assessments occur within a designated timeframe and may be paid or unpaid. If it is to be an unpaid assessment US Department of Labor criteria must be met.

Consumers cannot experience true, informed choice of employment unless they are given an opportunity to observe or experience different employment options. Therefore, it is critical that pre-placement opportunities occur. These experiences, while helping consumers make informed choices, also add to the assessment necessary for job placement.

Specific Challenges

- Many consumers of service have had few, if any, work related experiences and may not have the knowledge or background to make good career choices.
- Involving consumers who are non-verbal and/or have severe disabilities in the employment planning process.
- Involvement and buy-in from parents/guardians/care providers may not be present.
- Locating employers willing to provide situational assessment opportunities.
- Protracted planning and assessment; risk of planning "paralysis".
- Staff time and training for person-centered employment planning activities.
Practice Guidelines Related to Assessment of Leisure Skills

The goal of assessment of leisure abilities is first to determine the ability of the individual to make choices. This may be accomplished for leisure purposes alone, or may be part of a larger assessment effort aimed at self-determination in general. If it is determined that the individual has adequate choice making skills for their cognitive ability, leisure assessment should focus on determining what activities are preferred by the individual. A complete leisure assessment should include the following:

- A determination of the individual's ability to make choices and whether this can be improved through training, practice, or other supports
- A determination, if possible, of past experiences and opportunities the individual has had to choose and try out different leisure activities
- A determination of the individual's preferred activities (various methods may be needed to determine this including reports from the individual and/or significant others, observation of the individual, offering choices using pictures or objects, etc.)
- A review of barriers that may interfere with the individual's ability to engage in the preferred activities (these may be cognitive, physical, resource based, etc.)
- Assessment of available leisure activities in the individual's environment and in the surrounding community
- An evaluation of significant others that play a role in leisure activities including family, neighbors, housemates, co-workers, professional support people, etc.
- Assessment of existing natural resources in the person's life such as church, volunteer groups, etc.
  - A review of the consumer's and family's resources and natural supports.
  - Ascertain the hopes, dreams and desires of the consumer and family for long range planning.
- Discuss the specific results of the assessments with the consumer and/or family seeking their understanding and level of consensus.
- Providing information to consumers and their families to empower them to make decisions about needs and desires. This may include information about the organization, consumer rights, how to obtain access to various services, what services are available, understanding the difference between supports and services and so forth. Some consumers and their families may not need any help beyond this information.
- For consumers and their families who are having trouble accessing needed support and services because of complex needs, lack of resources, or other problems, the agency may provide or contract for assistance in the form of case management or supports coordination. These services must be provided in a manner that maintains the values identified above. They must be highly individualized and place the consumer's desires first.
If needed supports and/or services cannot be obtained through natural community resources, including regular health care plans, the agency may provide or contract for supports and services as necessary.

Working to improve availability and access to normal community resources for consumers with developmental disabilities.

Coordinating with other agencies such as the school system and health plans to aid in transition between services, avoid duplication of services, and make access easier for consumers and their families.

Ensuring that urgent/emergent needs of consumers with developmental disabilities are addressed in an effective, efficient manner.

Review the family's/consumer's wishes and reach agreement on short-term objectives to address two to three areas of priority to the consumer.

Obtain consensus from other caregivers for supports and interventions that build on the consumer's objectives and strengths.
Section VI

Practice Guidelines for Habilitation Support
Important Elements in a Supporting People with Developmental Disabilities

A. Build a plan!
1. Begin with Person Centered Planning Meeting
   - Identify hopes, dreams, and preferences of client and family
   - Prioritize life areas to include in plan for this year
2. Assess skills and obstacles in relevant life areas
3. Develop goals that
   - Are valued by client
   - Are attainable within the year (may include short term and long term goals)
   - Are clearly defined and measured
     - More specific than “gain independence”
4. Revise the plan yearly
   - Question goals with little progress
   - Discontinue goals that the client resists

B. Communicate Clearly- they may not tell you when they don’t understand
1. Be careful to use language that is not too complex
2. Use a calm tone of voice
3. Use a moderate rate of speech
4. Give instructions one step at a time
5. These strategies are especially important when the individual is taxed emotionally (under stress or upset)

C. Teach New Skills Effectively
1. Introduce one small skill or step at a time and then sequence steps into a behavior chain
   - For example, if you are teaching a new task of setting the table, the first step may be to ask the person to count out the appropriate number of plates
   - Are you sure of counting ability?
2. Plan for Generalization – create opportunities to practice newly acquired skills in different environments
Special Considerations for People with Autism Spectrum Disorders

1. Be aware of sensory issues (interests and especially intolerances)
   - Noise (volume and pitch sensitivity)
   - Personal space
   - Visual stimuli (bright lights, certain patterns or colors)
   - Tactile sensitivity (intolerance of touch, certain fabrics)
   - Taste aversion (extreme food selectivity)

2. Create an environment that maximizes structure

3. Provide cues to enhance the degree to which the routine is predictable (visual schedules)

4. Provide and teach and support a communication system to improve expressive and receptive communication

➤ Practice Guidelines Related to Supports for Self-Direction

Interventions should be implemented which address all the identified components of self-direction.

➤ Incorporating self-direction into the consumer’s attitude to self can be enhanced through repeated experiences of choice making that is rewarded by attainment of the choice and positive reinforcement related to the process.

➤ Improving consumer skills to express preferences, indicating choices and making decisions can be enhanced by teaching and allowing the practice of skills such as identifying important aspects of a choice, such as what is desirable about it, how to prioritize desires, identifying potential problems with certain choices, considering relevant issues such as cost, etc.
Promoting environments that support consumer self-direction. This would include staff attitudes, creative efforts to provide valid choices within available resources, tolerating and allowing consumers to learn from mistakes, etc.

Providing opportunities to try new options as part of being able to make an informed choice.

Consumer Interventions: The ability to express preferences and to make choices from among alternatives includes the two consumer skills that are central to self-direction. Improving limited communication skill is thus a key goal related to self-direction. For many consumers, including those with speech, alternatives should be pictured in addition to, or in place of verbal description. The alternatives presented should be those that are attractive to reasonable, non-disabled individuals, so that the expression of preference is meaningful.

Environmental Interventions: Improving the opportunity for exercising self-direction is primarily a function of staff orientation and training. The following standards should be followed:

- All professional and paraprofessional staff should be oriented to the value of mediating limitations on self-direction for consumers as part of training on Person-Centered Planning.
- All residential settings shall provide reasonable alternatives with respect to, at minimum: choice of dress, choice of food, choice of leisure time activities, bedtimes, and choice of roommate. Restrictions related to health and safety or presentation of alternatives must be included in the consumer's Person-Centered Plan.
- Staff training shall address methods for supporting consumers in expressing preferences and making choices.
- Service and Supports Coordinators shall monitor the degree to which an environment of self-direction is implemented in all service settings.

The ability to make decisions requires different skills depending on the complexity of the decision to be made. Deciding between two reasonable alternatives of what to eat for lunch may be improved solely by experience over time. However, making a life decision of the magnitude of choosing a place to live frequently requires specific training. Faw et al. (1996) describes a training process which leads to improved ability of all subjects to identify the important features of a living arrangement, prioritize them and determine which had to be present in order to consider the residence acceptable. Such a process should be part of the consumer's individual service and support plan when change in residence or work location is planned.

- Assess the consumer's understanding of Self-Determination and Person-Centered Planning (may use Arc's Self-Determination scale by Wehmeyer) and share results.
- Provide opportunities for consumer, family and natural caregivers to review self-determination literature, see videos, attend seminars at the local mental health agency, seek help from advocacy or peer organizations, etc.
- Facilitate the consumer's leadership for the Person-Centered Planning meeting, including time, place, attendees, content, and facilitator.
- Review any negative implications of the consumer's choice so that he/she is making an informed decision.
• Assist the consumer in documenting the dreams, hopes and wishes for his/her life, in describing his/her current situation and barriers to accomplishing these dreams. Help the consumer identify needed supports to improve areas related to functional categories and dreams.
• Insure that the consumer's meeting is carried out according to his/her plan and that those present acknowledge the consumer and not speak of him/her as a third party.
• Assist the consumer in reporting his/her dreams, barriers and wishes for improvement to the group.
• Ask the group to come up with ideas (brainstorm) that might help - promoting natural supports and community integration.
• Help the consumer obtain consensus. In the absence of consensus, weigh the risk of harm against the consumer's right of self-determination and choice. Recommend a level of risk that is tolerable but does not isolate the consumer's right to choice.
• Assist the consumer in selecting providers for his/her support, listing the cost of services and qualifications of providers.
• Encourage all involved to allow the consumer choice as often as possible and to assume responsibility for the natural consequences at a tolerable risk level. Encourage positive feedback and role modeling.

Best practice for self-direction involves creating essential lifestyle plans (Smull & Allen, 2000). Training is available and a manualized tool can be utilized. This method is a person-centered process that is developed, taking 30 – 40 hours. The planning clarifies what is important to the person with a disability. Such a plan can encompass best practice areas listed in this guideline.

Practice Guidelines Related to Supports for Health Management

Supports must cover a wide continuum of services aimed at assisting adults with developmental disabilities to manage their health care. Supports should cover the following general areas:

➢ Teaching/provision of information: Many adults with developmental disabilities can manage many or all of their health care needs independently if they receive information and teaching using modalities that work for them.
➢ "As needed": advocacy and/or assistance in interacting with health care providers: Advocates may need to be involved in promoting responsiveness of health care organizations/providers to the special needs of the persons with developmental disabilities.
➢ Interacting with health care providers on behalf of persons with developmental disabilities. This can include information and coordination meant to address physician's general concerns and support for individual consumers with specific problems.
➢ Providing support for health care procedures. This can range from education to personal and physical support from another person. Some individuals with developmental disabilities are fearful about certain procedures (e.g., gynecologic exams, dental work) and may benefit from in depth education, anxiety management may even require some level of sedation (Rosen, et. al., 1990).
Managing many aspects of health care for the consumer, if the consumer is unable to do it on his/her own and unlikely to learn how to do it independently. This can include health treatments, administering medications, assessing for the presence of identified symptoms and/or problems, etc. (assessing for symptoms may be very difficult, care takers must be trained and empowered to notice changes from normal physical and behavioral health and to report these changes).

Health promotion and prevention activities including exercise programs, stress reduction activities, and good nutrition should be available to consumers who are developmentally disabled. This could be accomplished through teaching, providing information, or providing and/or encouraging more formal activities in homes or elsewhere in the community. Examples would be attending programs at the YMCA, parks and recreation, senior center, exercise or walking groups, etc. Some health promotion activities should be tailored to the specific need of consumers (i.e., special cardiac fitness programs for at-risk consumers with Down syndrome) (Lancioni, 1998; Ridenhour & Norton, 1997; Pitetti, et. al., 1993; Rimmer et. al., 1993; Fernahall, 1992). Health prevention activities can include teaching of self-exams if the consumer is capable, keeping immunizations up to date, etc.

Harper & Wadsworth (1992) suggested that tailoring healthcare providers communication specifically to meet the needs of persons with developmental disabilities improved interactions. They demonstrated that without specific training in methods of communication, healthcare providers did not use basic communications skills. They used Making Contact: A Strategy to Train Health Care Professionals to Communicate with Adults with Mental Retardation. Enhanced communication behaviors are: Leveling (speaking at equal eye level), declarative sentence structure (information describing the speaker’s world is provided and accompanies the actions of the speaker), open-ended questions (results in reduced acquiescence by a person with developmental disabilities with a desire to please the healthcare professional), provide corrective feedback (permits correction of fact and reinforces participation), remove distracting objects, and remove distracting people. Supports include the following areas:

- Ensure that supports include opportunities for the person with a developmental disability to be reinforced for participation in a social environment (e.g., recognition by the listener of the communication intent by the speaker and a resulting social environmental change).
- If language is unclear, caregivers need to understand the communicative intent of facial expressions, non-verbal utterances, and gestures.
- Supports that address communication behaviors by caregivers, including training and education related to enhancing communication for individuals with developmental disabilities.
- Use contextual cues to enhance meaning.

**Best Practice Related to Supports for Safety Management**

Personal safety may be jeopardized by careless, high-risk behaviors and an inability to appropriately react in emergency situations. Often a lack of knowledge about resources to utilize in an emergency is problematic as well as an inability to interpret or abide by safety signs. In many cases, excessive friendliness with strangers and other factors caused by "overprotection" in the past may place the consumer at risk.
Environmental modifications should be made as necessary, based on the safety needs and abilities of the consumer and the structure of the environment. A balance should be attempted between having a safe enough environment to allow significant freedom of movement and decrease the need for close supervision and allowing consumers access to as much of the community as possible.

Sex education, focusing on what behavior is appropriate under what circumstance and emphasizing assertiveness and reporting techniques if the consumer finds themselves in a problem situation (Lumley and Miltenberger, 1997).

Identifying priority safety needs and developing individualized programs to address these systematically.

Making environmental adjustments to reduce risk and improve safety, especially when safety issues are related to physical disability or sensory impairment.

Providing fire safety training and evacuation training for consumers who are capable of appropriate response, ensuring supports, for those who cannot. Behavior training programs using chaining and backward chaining may be effective if consistently applied (Bannerman, et. al., 1991). An example of supports would be ensuring adequate staff to evacuate consumers with disabilities in case of fire.

Safety training should occur as much as possible in the environment where the consumer will need the behaviors.

Education aimed at prevention of abuse, victimization, and fraud should be provided that is tailored to the cognitive abilities of the consumer.

Personal instructions about never going with strangers, staying in groups, and never telling anyone he/she is home alone are helpful.

Role-playing may be utilized and educational games used for practice.

Using pictorial and verbal examples, asking for responses and teaching which resources to use are important. This might include various types of emergencies: poisons, cuts/bleeding, fire, etc.

Teach the consumer to use emergency numbers. Post numbers and pictures by the phone.

Teach safe places in the community such as a store, church, etc. if the consumer is afraid.

Help the consumer identify animals they should not approach.

Teach the use of seat belts (when in a vehicle) and safety signs for crossing the street, when walking or biking.

Help the consumer understand he/she should not accept pills or food from unknown persons.

**Best Practice Related to Supports for Social Skills**

The current literature uses mostly reversal design, pre-test/post-test, and multiple baselines across subjects and responses to evaluate validity. Two primary intervention issues are addressed. The first issue is the type of intervention with most of the literature discussing direct modification of observable behavior through modeling, prompting, behavioral rehearsal, contingent reinforcement and corrective feedback techniques (Huang & Cuvo, 1997; Castles & Glass, 1986; Valenti-Hein, et. al, 1994; Wildman, et. al., 1986; Lalli, et. al., 1991; and Park & Gaylord-Ross, 1989). Huang & Cuvo
(1997), report six distinct types of intervention: modeling, social skills training packages (include instruction, modeling, role-play, and social feedback), peer-mediated strategies (competent coworkers are taught how to provide stimuli and deliver consequences designed to improve social skills), self-management training (performing one of the following functions: recognize a problem, instruct oneself to solve the problem, monitor the performance of the action, and evaluate the performance), consequence management (identifying and systematically changing antecedents and consequences to define observable behavior), and process training (similar to self-management with the exception that the activities occur relative to a defined social rule). Training in these studies was reported to have occurred in both group and individual training sessions.

Also, frequently reported in the literature are various uses of the Stacking the Deck game developed by Foxx, et. al., (1983). For example Langone, (et. al., 1995) reported using this structured program to teach the six social skills targeted through the program: compliments, social interaction, politeness, criticism, social confrontation, and questions and answers. One variation to teaching specific behaviors is to intervene using Process Training (Huang & Cuvo, 1997). This variation involves decoding social cues in context, identifying alternative responses and evaluating the best response, performing the behavior, and evaluating its effectiveness. Park & Gaylord-Ross (1989) reported superior results using this model with participants diagnosed as moderately or mildly mentally retarded. This intervention variation was developed to address the second major issue reported in the literature: generalization. Problems related to generalization of social skills to natural situations are reported throughout the literature (Langone, et. al., 1995; Park & Gaylord-Ross, 1989; Castles & Glass, 1986; Huang & Cuvo, 1997; Ralph & Usher, 1995; Lalli, et. al., 1991; Wildman, et. al., 1986; and Valenti-Hein, et. al., 1994). In addition to process training, these studies address generalization by carefully selecting target behaviors to match situations the learner would be confronted with in a natural setting (Lalli, et. al., 1991), having participants select a social problem to work on (Valenti-Hein, et. al., 1994), training in community based settings (Huang & Cuvo, 1997), and programming of common stimuli within the treatment and generalization environment (Park & Gaylord-Ross, 1989). Specific supports may include the following:

- Use of the Person-Centered Planning process to identify individuals chosen by the consumer to participate in identifying hopes, dreams, and wishes that might be met through improved social skills.
- Seek larger community feedback on targeted areas for social improvement (e.g., survey supported employment employers on social skill areas where they think improvement would result in more successful employment for consumers).
- Utilize training of specific observable and measurable behaviors with approaches that allow for repeated rehearsal by the Consumer across time, place, and settings. Examples are modeling, behavioral rehearsal, role-play, corrective feedback and practice, and contingent reinforcement. Allow ample opportunity for practice.
- Program specifically for generalization:
  - When possible, train in community based or natural settings.
  - Program common stimuli (i.e., situations resemble the natural situation).
  - Ask consumers to select the work on items they see as important.
  - Use process training when possible.
Select interventions to target problems most often seen in the consumer's environment of choice.

Plan for reinforcement of effective social skills in the natural environment. Provide education for families and others about how to do this.

For individuals who use alternative communication methods, supports may include assisting or teaching others to understand the individual and/or acting much like an interpreter. Coaching, or on-going prompting, may be appropriate while individuals are learning new skills or as a long-term support.

Teach the consumer about different emotions and how to identify "triggers". Assist the consumer in healthy ways to express negative emotions using role-playing, pictorial techniques. Encourage others to promote independence in social situations by encouraging the consumer to handle problems. Reinforce appropriate handling of negative emotions & problems.

Practice Guidelines Related to Support of Self-Care

Supports for self-care activities range from complete physical care for individuals who are severely physically and cognitively disabled to simple reminders or refinements for very high functioning individuals.

Environments should be modified as necessary if they present barriers to performance of self-care activities. Examples could be as simple as making materials necessary for self-care easily accessible, providing privacy, making sure there is enough time to do the task, or ensuring access to areas where self-care takes place, such as the bathroom.

Adaptive devices should be utilized as appropriate to increase individual independence. Physical and/or occupational therapist involvement may be necessary to determine the best device(s) to use and to develop training plans for the consumer/caretakers/significant others in the use of the device.

Supports designed or monitored by medical professionals may be necessary for some individuals. For example, individuals with swallowing problems should have a professionally designed plan to provide food in a safe manner by altering texture, presentation and delivery method. Feeding tubes may need to be monitored by registered nurses; mobility programs may need to be designed by occupational or physical therapists.

If the consumer has numerous self-care deficits, care should be taken to prioritize need based on health and safety issues and consumer preference, so the consumer is not overwhelmed by too many new tasks at once. It may be determined that the effort necessary to train and maintain certain skills is not in the best interest of the consumer or is contrary to consumer preference. Supports may be more appropriate in such cases.

If it is determined that skills training may be appropriate for a consumer, specific cognitive deficits should be identified, if possible, to help determine the best approach to self-care skills training for each individual. Some techniques that have been successful include task breakdown (analysis), chaining and backward chaining (linking small pieces of a task together), repetition, different ways to present material (i.e. visual symbols, auditory teaching, physical modeling, etc.) and so on. The use of verbal and physical prompts, hand over hand
guidance, picture boards, etc., and helpful positive reinforcement of performance is almost always helpful (Matson, et. al., 1998).

- Consumers should be assisted in the self-administration of medications. When medications are not self-administered, specific protocols must be followed. People living independently may have daily medication drops to home or pre-packaged dosages.
- The caregiver must assist the consumer in obtaining assistance in getting medications, may need to access low cost or free programs, and advocate for generic drugs when appropriate.
- The consumers and caregivers should be educated about the medications, their side effects, and lifestyle changes that may reduce side effects.
- Discuss the consumer's feelings about taking medication and help the consumer identify how the medication has reduced symptoms.
- The caregiver should arrange for an annual physical exam and bi-annual dental exams and cleaning, and any other assessments necessary.
- As necessary, design and implement behavioral plans that reinforce desired behaviors using techniques that reinforce those behaviors such as shaping, fading, extinction, or differential reinforcement. Educate care and family members to ensure consistent implementation.
- Assist the consumer in acquiring necessary adaptive equipment and consults for suitable gross motor training and positioning that will help in self-care.

**Practice Guidelines Related to Supports for Home Living**

Supports for residential services must be highly individualized even in traditional residential settings.

- Supports can range from complete care, including maximum assistance with basic self-care, to minimal assistance with occasional complex problems.
- Residential settings should be chosen based on consumer preference and whether the supports desired, and needed by the consumer can realistically be provided in that setting.
- Reasonable environmental modifications to increase independence should be considered (professionals with the appropriate expertise should be consulted to maximize the efficacy of such modifications).
- Community services such as personal emergency response systems and home delivered meals should be utilized as appropriate.
- Respite services should be used as necessary to maintain residential settings during times when regular caretakers or support people are unavailable to prevent having to move the consumer to a different setting.

**Judicious use of respite services can prevent loss of natural residential resources.**

**Home Living**

The Personal Care Level of Care Assessment tool helps caregivers discuss with the consumer and family members the amount and level of support needed for medical issues, safety concerns and personal care.
After development of a master list of the consumer's wishes and needs, natural resources and financial options, they should be matched to available housing options. In developing the list of needs and wishes, the caregiver must provide feedback on parameters and availability of things like financing, barrier free design, access to public transportation, etc. The consumer and family, after choosing some options, should visit the housing environment. Once the choice is made, the caregiver must assist the consumer in moving into the residence and visit frequently at first to understand and provide support for any feelings of fear, etc., that the consumer may have.

The consumer must be allowed to choose with whom they live.

In all instances, the consumer should be educated in how to contact the Recipient Rights staff in case of abuse or neglect.

In more independent settings, the caregiver will need to assist the consumer in setting up bank accounts, turning on utilities, etc.

The caregiver should report any violations of the Fair Housing Amendments Act or the ADA to Recipient Rights.

Practice Guidelines Related to Supports for Community Use

Supports for community integration will require coordination of supports from other functional domains. When considering supports, they should be considered in this order:

- Person
- Family and friends
- Non-paid supports
- Generic services
- Specialized services

This is a significant shift away from reliance on system supports to meet needs. Reliance on artificial supports implies that persons with disabilities are not actual members of their communities. Planning for life stage transitions should always be considered in advance of the transition. Individuals may need support to become aware of new opportunities that are available to them as they enter adulthood or become senior citizens.

Supports for community use cover an extremely wide array of activities. Such supports should always be designed so that the individual participates in an activity as an equal partner. For example, if a support person must accompany an individual with developmental disabilities on a shopping trip because they are unable to count change, that is the only activity that should be supported and as unobtrusively as possible. Individuals should also participate as fully in the activity/resource as possible. For example, it would not be appropriate for a group of individuals with developmental disabilities to sit in the waiting area of a bank while the support person cashes all of their checks or to sit by the lane at a bowling alley while the support person goes to pay fees and rent shoes.

For persons without disabilities, it is not necessary to have a written plan to define how we will interact in our community. Unfortunately, for persons with disabilities, it is necessary to record
roles and responsibilities to ensure that this important part of their life is not neglected. Based on
the assessment information and Person-Centered Planning, a written plan should be developed that
defines who will be responsible to carry out each function. It may be necessary to share information
about the nature of supports and community use with caretakers, family, and others involved as they
may be accustomed to a very different approach. The plan should be reviewed at regular intervals to
determine if it continues to meet the needs of the consumer. There will likely be barriers that need
to be addressed as time goes by.

When considering places in the community to access, it is essential to consider all the resources
available in the immediate community. Retail shopping is usually a popular choice for community
outings. It is important that retail outings be used as a great learning experience. For example,
persons should be given opportunities to interact with store personnel by making inquiries about
items they are interested in. Learning how to find what your size is, where they keep your size, how
to pick out clothes to try on and the procedure for doing so can be an ongoing shopping experience.
It is also helpful for the person with disabilities to have multiple opportunities to try the same or
similar activities. Learning and increased independence comes through repeated trials. Restaurants
are another popular choice, usually requiring at least the price of a cup of coffee. Restaurants
provide great opportunities for interaction with wait staff, learning to understand a menu and
appropriate social manners when eating in public. Other service oriented community resources
include banks, laundry, grocery stores, post offices, and libraries. Leisure and recreation resources to
consider include bowling alleys, movie theaters, skating facilities and local recreation facilities such as
the YMCA. Deciding where to go will depend on the individual's desires, resources (including
financial), accessibility, and supports available to make it happen.

The goal of community use/integration/inclusion is nothing less than the full participation of the
person with disabilities in his or her chosen community. The question should not be what does this
person need to attain to participate, but rather, what supports are necessary to make full
participation a reality.

The major supports issues related to community use include limited access to shopping, worship,
parks, libraries, theatres, and businesses. There are difficulties in recognizing and understanding
common public information signs; to communicate personal information such as address and phone
number, to pay for goods and make change and to utilize public transportation.

- Safe training sites should be developed in the community to provide the consumer with real
  opportunities in the community areas listed above.
- Instruction and feedback on common signs may be necessary, including street signals,
  restrooms, elevators, etc.
- Assist the consumer in obtaining an identification card.
- Practice the skills to utilize public transportation including trial runs to ensure the consumer
  knows how to pay the fare, what landmarks tell him/her when to get off and how to ask for
  assistance if confused or the bus does not come.
- Provide assistance in entering social groups, such as churches, etc., where natural supports
  and relationships can be developed.
Practice Guidelines Related to Supports for Functional Academics

Functional academics skills are well suited for supports if learning them is especially difficult for the individual or the individual is not motivated to do the work necessary. Many individuals without developmental disabilities are functionally illiterate. Although this poses some problems for them, many are able to function very well in the community. A common example of supports seen in the community today is the almost universal implementation of cash registers that calculate change so the cashier does not need to know how to make change. Any training aimed at increasing functional academic performance should be conducted in the setting in which it will be needed, focusing on the particular outcomes to be achieved. Supports must be highly individualized based on each consumer’s circumstances. Adaptive training and supports can include the following:

- If training will be conducted to teach academic skills, design teaching methods that address specific cognitive problems if they are known. For example, repetition may be appropriate for memory deficits, but not problems with auditory cues.
- Provide training in a creative, interesting manner with liberal reinforcement when academic skills are to be learned.
- Give plenty of opportunity to practice the skill in the settings in which it will be or is needed.
- Supports for activities requiring academic skills can be many and varied. Functional symbol devices, auditory recordings, coaching, and identification of ways to achieve outcomes without needing academics are just a few suggestions.
- Some individuals can benefit from existing adult education resources and literacy programs. Investigate these before developing duplicate training that does not promote community integration.

Often aging in this population can result in cognitive decompensation such as confusion, memory loss, inability to learn new tasks, deterioration in personal skills and physical health. Caregivers should attempt to:

- Maintain existing activities of daily living in age appropriate settings
- Use adaptive equipment to continue support for independence
- Seek appropriate medical consultation as for the general aging population
- Identify with the consumer any retirement plans and wishes
- Maximize choices & preferences
- Rule out pharmaceuticals as causal variables
- Review with the consumer and family appropriate residential options related to level of risk and self-care.
- Continue to utilize, as necessary, behavioral plans for strengthening desirable behaviors.
- Encourage continued socialization and relationships to avoid depression while strengthening supports.
Practice Guidelines Related to Supports for Employment

Job Development and Placement: Job development is planned based on the information gathered in the vocational assessment. Job development should not be random, but rather focused on the individual's interests, abilities and supports available. Transportation must be arranged when necessary. Transportation availability and cost must be considered. Wages and benefits should be equal to that of a non-disabled employee. The job coach may need to educate the prospective employer about the financial incentives available, as well as the benefits of employing disabled workers.

The job developer must approach the employer with alternatives to meet the employer's and the consumer's needs. The survey research of Mank, (et. al., 1998) clearly demonstrates the importance of the initial development and negotiation of the job. One of the most important aspects appears to be that the job is developed to be as “typical” as possible. That means having the job must be as much like that of a non-disabled employee as possible, including how the job was obtained, the work the person does, and how much the individual is paid.

Methods of adapting work for the person with developmental disabilities such as job sharing and job shaping (breaking the job down into small parts to allow the developmentally disabled individual to learn it) may be necessary. Examples of job shaping to smaller tasks include rolling silverware into napkins at a restaurant, thereby freeing waitresses to complete more complex tasks, or cleaning glass surfaces at a supermarket rather than all the janitorial duties usually included in the job description.

Job development and placement should not be reserved for higher functioning individuals. Data reported in 1997, indicated that 87.6% of persons with a mental retardation diagnosis in supported employment had a mild, moderate or borderline diagnosis. Those with severe mental retardation, behavioral challenges and multiple disabilities are significantly under-represented among those participating in supported employment (Wehman et al., 1996). All persons desiring to work should have, as a component of their Person-Centered Plan, how this end result is to be achieved.

Job Training and Supports: Supports for a job must cover all identified deficits. The following are essential:

- Cognitive deficits will usually require some form of task analysis to determine the best way to teach basic skills and the specific skills needed for the job. Cognitive deficits that cannot be effectively removed or diminished by training may require on-going supports.
- Physical deficits may require adaptive techniques or devices. An occupational therapist can often assist in making recommendations for such accommodations. A good example would be to have a work surface at the appropriate level for a consumer who uses a wheelchair..
- Problem behavior that interferes with ability to work should be addressed by a plan developed by a behavior specialist such as a behavior psychologist, following professional assessment.
- Everyone has positive attributes and strengths. These abilities must be built upon.

Each job is unique in its expectations and environment. This is why it is recommended to train to the actual job task when the job is acquired rather than spending a lot of time with pre-vocational training. Persons with ineffective ability to generalize will not benefit greatly from training that
occurs outside of the work site. The job coach will perform task analysis prior to the employee's start date. This involves separating each type of function required and breaking each task into steps. The employee will receive on the job training by the job coach and other on-site employees that will be working with the employee. Natural supports are critical to the success of the placement. It is important to have other employees invested in the success of the placement and to form co-worker relationships. Research has shown that the most successful placements are at work sites where there are strong co-worker relationships (Mank, et al., 1998). Persons receiving employment supports should have the opportunity for career advancement. Career changes and advancement are a natural progression in an individual’s life.

### Practice Guidelines for Job Development

Job development should be viewed as a natural extension of career planning and assessment. The Person-Centered Employment Planning approach should identify types of jobs, work environments, quality factors, accommodations and supports needed by the individual. Job development begins with those factors in mind.

Individuals are involved to the greatest extent possible in the job search process. Job development occurs with specific individuals in mind and is based on their personal skills, abilities, preferences and assets. Locating jobs without specific consumers in mind decreases the likelihood for compatible job/worker matches and job retention. Focusing job development efforts with a specific individual in mind allows the developer to:

- Describe a specific candidate's skills and assets to an employer.
- Focus on specific types of employment situations that match with the preferences, skills and needs of the individual.
- Utilize the individual's personal marketing tools (resume, references, etc.) that are typical to finding a job.

Job development will be different for each individual given the varying abilities to assist with the process and their level of support needs. Job developers require a good working knowledge of the Americans with Disabilities Act (ADA) and their own agency's policies on disclosure and confidentiality. Job developers must understand the limits of inquiry imposed by the ADA, and work with consumers in developing strategies that address how, when, and under what circumstances disability will be discussed. It is always best to discuss the functional abilities of the job candidate and describe them in terms of their competencies and skills.

The "art" of networking is key to good job development. Knowing and understanding the networks of your community is key to effective job development. Relying solely on the want ads in the local newspaper is not an effective method of job development. Service providers must establish partnerships with the business community and must have a marketing strategy that is consistent with the agency's overall mission and purpose.

The business community is viewed as a secondary customer and partner in the supported employment endeavor. Effective job developers will identify employer needs, establish a "fit" with the candidate, the services to be provided and the employer's needs, and assist the employer to
understand the benefits of hiring the individual and working with the service provider. It is essential that job developers possess excellent communication skills and have the ability to easily articulate the value of such a partnership.

Job development activities need to be tracked and documented. This requires good time management and accountability on the part of the job developer. Following up on job leads, developing sites for situational assessments, participating in consumers’ employment planning meetings, touring a job site with a job seeker, or researching information about a company are just a few of the tasks that a job developer may engage in during any given week. It is important for funding and cost effectiveness that activities are tracked and documented. Job developers need to set specific goals and timelines for development activities with each individual. Time between intake, assessment, and job placement should also be documented. Service providers need accounting mechanisms to track all development activities such as number of contacts, number of placements, types of job placements, follow-up contacts and hours spent in job development activities.

Specific Challenges

- Locating employers and jobs that match consumer "profiles" and desires.
- Addressing employer concerns related to working with individuals with disabilities.
- Recruiting job developers from the human service sector who possess the necessary skills and knowledge for effective job development.
- Overcoming the stereotypes and stigma attached to disability by the community at large, and the possible stereotypes/stigma attached to the agency and its consumers.
- Developing marketing strategies that are targeted toward the business community that communicate "ability" vs. disability.
- Identifying transportation options individually rather than systematically
- Locating jobs for persons with severe disabilities and/or high support needs; staff who has the skill to recognize opportunities to "carve" out positions and employers willing to consider such possibilities.

Practice Guidelines for Implementing Supported Employment

Worksite and Task Analysis

Prior to placing an individual on a job, the job developer/employment specialist will want to conduct a worksite analysis. This is a systematic approach that describes a specific work environment. It includes:

- Description of the environment in which the work is performed that includes safety and work culture.
- The social, intellectual, and physical requirements of the job
- The elements of the job itself, the tasks and skill requirements

The job developer will already have obtained some of this information; however, it is important that the employment specialist doing the training review and clarify the information with the employer.
It is always a good idea for the employment specialist to visit the worksite prior to the individual starting a job to assess and address any issues related to safety or expectations of the job. Service providers should have documentation for completing a worksite analysis.

Jobs that include tasks that may be problematic, viewed as too complex for the worker, or which require multi-steps will need to be broken down into behavioral components or presented by a task analysis. This task analysis is a training tool, constructed by the employment specialist (trainer) as his/her guide to understanding and teaching the task. The task analysis is designed to provide focus and consistency across time and trainers, and to facilitate and document skill acquisition (Buckley, Mank, & Sandow, 1990). It is the sequential list of activities or behaviors required of the worker to complete the task. Task analysis is the foundation of systematic instruction.

**Instructional and Support Strategies**

Training job skills in community settings and meeting employer expectations are far removed from the training and instruction that consumers receive in day activity or sheltered workshop environments. The selection and introduction of support strategies depends on a foundation that consists of job analysis, environmental and task modifications, precise and systematic methods of instruction, and ongoing performance assessment (Buckley, Mank, & Sandow, 1990).

Instructional and support strategies provided by the employment specialist should be developed with consideration of the consumer’s experience, learning style, complexity of the task(s) and the working environment. They need to implement instructional strategies to enable the consumer to succeed in the performance of specific job tasks. Employment specialists/job coaches need to understand the principles of systematic instruction, but also be able to facilitate interactions between co-workers and the consumer for the purposes of training and support. The involvement of coworkers, supervisors and corporate management must be encouraged. The interaction of these support sources will lead to improved consumer and program outcomes, consumer, family and employer satisfaction, and most significantly access to integrated opportunities in the workplace (Buckley, Mank & Sandow, 1990).

Providing training on specific work skills to enhance existing supports on a job is the function of the employment specialist. Consumers who possess the ability to perform tasks to employer’s expectations are likely to be successful in maintaining their employment. However, many individuals lose their jobs because they lack appropriate social skills (Brickley, Campbell & Browning, 1985; Hill, Wehman, & Goodall, 1986). In addition to training work skills, the employment specialist is charged with teaching and training social skills that will enable consumers to become part of the social network of the workplace. It is important for employment consultants to communicate to consumers that their social behaviors affect environmental and interpersonal relationships on the job.

Training data collection systems must be in place to track consumer progress and independent performance as well as evaluate the entire supported employment process. Data collection is used to interpret training outcomes, identify additional support needs, track time and efficiency of the employment specialist, and provide a cost/benefit analysis that looks at all impacts, not just those valued in dollars.
Specific Challenges

- Staff competent and knowledgeable in methods of systematic instruction.
- Ensuring staff time and funding for pre-placement activities like worksite and task analysis.
- Resources for developing work opportunities and training individuals in community jobs that have significant disabilities and high support needs.
- Staff that is specifically focused on employment outcomes and training.
- Familiarizing the business community with supported employment processes.

Providing On-going Employment Supports

Intensive job coach training was never intended to go on indefinitely. However, one of the fundamental characteristics to supported employment is the provision of post-employment support. Because individuals grow and change in relation to their work experiences, the rationale for providing on-going support services is not simply to maintain employment, but to provide opportunities that result in career advancements, increased wages, new job responsibilities, etc. (Hughes, Rusch, & Curl, 1990). Individuals must be provided with on-going support services to maintain employment for as long as the Consumer is employed at the supported employment job.

The employment staff assigned to provide "follow-along" or on-going support services assumes a role that includes maintaining or extending Consumer competence as it relates to their employment. The focus is to teach consumers strategies that help them adapt to new expectations or responsibilities on the job, changes in supervisor/co-worker personnel, or maintenance of independence in meeting performance standards. Providing "follow-along" supports and activities might mean jobsite interventions to resolve specific problems or support away from the job with issues or situations that directly impact the Consumer's ability to maintain employment.

On-going support services are not time-limited. Federal guidelines require that a minimum of two (2) Consumer contacts per month be made after intensive job coaching has ceased. These contacts may be made at or away from the worksite, wherever is deemed most appropriate. Consumer and employer need should always dictate the method and schedule for ongoing support services. Extending Consumer competence by promoting independence allows supported employees to adjust their performance in relation to varying demands of the job and expands their opportunities and enhances their career potential.

Specific Challenges

- Determining staff assignment. Should employment staff, i.e. employment specialists, or supports coordinators assume the duties of "follow-along"?
- Responding to consumer/employer concerns in a timely fashion by ensuring staff is available for employment "crisis intervention".
- Ensuring that a reporting and documenting system is in place that "red flags" any potential concerns, issues, or problems.
Coordinating services and communication across different departments when employment staff is not identified as a "follow-along" provider of service.

Identifying and responding to appropriate support needs of consumers.

While maintaining a concern for job retention, also recognizing when career exploration and renewed job developments may be appropriate.

Consumers risk losing Medicaid benefits as a result of earning too much money. The State needs to correct this problem to the extent allowed under Federal law.

Organizational Accountability and Documentation for Supported Employment Programs

Public agencies providing services to individuals with disabilities are responsible for ensuring that funds are directed toward the purpose for which they were appropriated, that individual rights are protected, and that the services purchased result in desired outcomes. Measures of outcomes, wages, hours, retention, satisfaction, etc., provide the focal point for program administration review. Outcome or results-based management of social service programs is replacing the traditional regulation process of accountability (Miller & Miller, 1981). However, reasonable oversight is still required. Health, safety, and concerns for individual rights will require some process regulation. Examples of process regulations that need to be in place include:

- Demonstration and documentation that support/service plans consider and respect individual choice; include the input of the individual and significant others; the choices that are to be implemented, and the actions and responsibilities for implementation.
- Oversight and monitoring of support plans is assigned to relevant professionals.
- Outcome in the support plan is achieved.
- Regular assessment of Consumer and employer satisfaction is completed.
- Reasonable standards for health and safety are met.

Supported employment outcomes relevant to best practice and quality of life for individuals being served include:

- Individuals working 10 or more hours per week
- Individuals earning at least the federal minimum wage or above
- Individuals maintaining jobs after 6 months; after 1-year service.
- Reason for job separation
- Time between referral and employment
- Evidence of choice and job satisfaction

Staffing supported employment programs is critical to successful outcomes. Employment staff must demonstrate core supported employment competencies that include:

- Building and maintaining relationships with employers
- Completing a worksite/jobsite analysis
- Writing a task analysis
- Training by systematic instructional methods
Practice Guidelines in DD

- Developing natural supports
- Training social competencies
- Collecting and reporting training data
- Developing or modifying a worksite
- Systematic fading of onsite training interventions

Staff competencies, turnover, and satisfaction should also be documented on a regular basis.

**Specific Challenges**

- Developing and implementing service documentation that is user friendly and usable to providers.
- Responding to indicators that demonstrate areas where service delivery outcomes need improving.
- Recruiting, training and maintaining competent staff.
- Consistent and on-going review of documentation and quality indicators.

**Practice Guidelines Related to Supports for Leisure Skills**

The Person-Centered Plan should include ways to increase choice related to leisure activities. This may range from giving the individual practice with simple choices between two (2) concrete objects, to educating the person on available community activities, and assisting the individual to try them before deciding what they like to do.

- Adults and children with developmental disabilities should be exposed to a wide variety of leisure activities that are within their resources to pursue. Choice is not possible without choices.
- Transition planning for life stage changes, such as from school to adult living and work, or from work to retirement, must be included in the Person-Centered Plan as appropriate.
- Reasonable adaptations for environmental and physical barriers to leisure participation should be determined and considered (this includes such issues as transportation, supervision, adaptive devices, etc.)
- Community activism may be necessary to develop inclusive activities for all individuals.
- Participation in community activities should reflect how that activity is usually done. Care should be taken not to draw attention to differences if at all possible.
- Care should be taken to assist the individual in promoting safety while participating in the activity, such as protective headgear while biking, and attending social activities in safe places, but individuals should be allowed a reasonable and normal amount of risk within their ability to make such a determination.

Most communities have a recreation facility, possibly a YMCA, college facilities, or a community recreation center or department. Many city-sponsored activities are low cost or cost can be
negotiated for those with low income. Check the phone book, newspaper, local cable network, Chamber of Commerce, and city government to learn of available resources.

Senior Centers are paid for or supported by local, state and federal government money. They provide many free services to senior citizens over the age of 50. Meals, activities, transportation, and socialization can be an ideal environment to meet many leisure needs. It is recommended to provide supports or recruit supports to help persons with disabilities integrate into the senior community. Some persons will be able to have their supports fade until they can be independent within the senior center. Individuals should not be dropped off without supervision or supports. Alienating community service providers is a serious mistake. Coaches can accompany disabled seniors, helping them to establish relationships and participate in activities. These coaches must be prepared to participate right along, interact with other senior participants, and form supportive relationships. Care must be taken not to over integrate the center. Studies have shown that if an environment like a senior center is integrated greater than the normal population, then the non-disabled population may begin to find other places to socialize.

Relationships

Building relationships is one of the most neglected areas of growth and skill building for persons with developmental disabilities. Hughes, (et. al., 1995) reported that the dimension most frequently cited as important in determining quality of life was social relationships and interactions. The focus on leisure has been to engage people in activity rather than building social relationships. Providing opportunities for engagement in activity is positive and encouraged, however, the need to develop relationships should not be overlooked. Persons with supportive family members tend to have more relationships that continue over time. Persons with limited social networks need staff to consider supports for their relationship needs. It is important to encourage relationships among individuals living in a household together, as well as developing new relationships outside of the home. Potential resources include community, school, and college volunteer programs. A good example is the Best Buddies program established by Anthony Kennedy Shriver in 1987 to pair college students with persons with disabilities with the main goal of friendship building.

Practice Guidelines – Dangerous Behavior

Certain disruptive and dangerous behaviors require specific attention. Those behaviors include substance abuse, violence, elopement, fire setting, and sexually inappropriate behavior. Sometimes the consumer faces legal involvement and occasionally requires restrictive care.

- Always take immediate steps to protect the consumer and those in his/her environment.
- Upon identification of the behavior, the caregiver must arrange for appropriate physical, psychological and psychiatric assessments to identify/rule out specific mental health and biomedical contributions to the problem such as pain, epilepsy, psychiatric disorder, sexual abuse, brain tumors, etc. This is especially important if the behavior is new.
- Record antecedent events to behavior and discuss the behavior with the consumer ascertaining his/her feelings. Have family or caregivers collect baseline data on the frequency and type of behavior.

- Meet with the consumer/family and provide assessment data and seek understanding. Explain the consequences of continuing certain behaviors. It may be necessary to repeat these consequences over a period of time for the Consumer to understand.
- Discuss and teach appropriate behavior through role modeling, via video or pictures.
- Develop and implement a behavior plan and a crisis plan, educating the consumer, family, and all caregivers for consistent implementation. It is most helpful to obtain the consumer’s consensus on reinforcers and/or consequences.
- The plan should be monitored regularly and progress noted. Intervals should be frequent enough to provide positive feedback to the Consumer that is valuable and to modify the plan if it is not working.

**Special Note:** A pattern of illegal behavior may result in legal charges and even incarceration. For non-felonious charges, the jail stay should be diverted. In other situations, a forensic evaluation will be necessary to determine the consumer’s criminal responsibility and understanding of the charges against him/her. The clinician should maintain contact with the consumer and family. The caregiver and family should not protect the consumer from the legal consequences of behavior if he/she has the capacity to understand the implications of the behavior. The consumer should be confronted if he/she attempts to blame others. The caregiver may work with probation/parole officers to implement needed community supports and safety restrictions for successful community reintegration.
A GUIDELINE FOR CONSUMERS
AND THEIR FAMILIES

What does it mean when someone tells you that you have a developmental disability? It means that you have one or more serious problems that started before you became an adult. These problems usually last for a person’s whole life. Because of the disability, three or more of your major life areas are very limited: self-care, hearing or talking, learning, physical movement, self-direction, living alone, or making a living. These disabilities can be called pervasive developmental disorders or mental retardation. Pervasive developmental disorders are often defined by impairments in social interaction, communication and the presence of repetitive types of behavior such as those seen in Autism and Asperger’s Syndrome. Mental retardation is defined by problems in thinking and may be profound, severe, moderate or mild. You must have an evaluation by a social worker, psychologist or doctor to know if you have a developmental disability.

Some people with developmental disabilities may also have other types of problems more frequently than the rest of us: health problems, dental problems, earlier aging, side effects from medications, difficulty coping with evaluation and treatment, problems with weight and exercise.

Because of the problems mentioned above, you may need life-long supports to reach your goals and to live the life you want. Sometimes these supports start in school where you may learn academic skills and other functional skills such as how to ride public transportation, how to make a bed, how to budget money and shop, or how to cook. You may have also identified some goals for the type of work you may do later in life. When you are an adult, your care may be provided by a local developmental disabilities agency. The school and the developmental disability agency should meet with you to plan the change from school to adult life. The meeting will include you and your family members, other people in your life (when they are important to you), school personnel and representatives of the mental health agency. This transition-planning meeting will help you identify the ongoing supports you need.

Once your care is being provided by the mental health system, you will have a very special type of planning called “person-centered planning”. This is a way of helping you identify the supports you will need to achieve your hopes, dreams and desires. This type of planning will help you build a plan for community life and will honor your preferences, choices and abilities.

Person-centered planning starts with a worker helping you name people that you might want to attend a meeting to help you plan. These people might include your mother, father, sister or brother and other family members. You could also invite neighborhood friends, friends from school, your teachers, people from your church, or people who are part of groups that you belong to. Finally, you may include other workers who are helping you to reach your goals. It can include anyone that you want to have at the meeting. You can also decide if there is anyone that you do not want to have at the meeting.

There are many ways to help you plan. Planning must be done in a way that makes you feel comfortable. The goal of planning is to help you reach your dreams for the future.

The plan should include:
- Supports and strengths that you have;
- Supports from your family, guardian, friends and significant others;
- Any resources available to help you in the community or in your neighborhood;
• Other public supports available to anyone in the community, and finally;
• Supports and services you need from the developmental disability agency.

To help with this planning process, you and your family and friends will be asked things like:
• Where do you want to live?
• How do you want to spend your time each day?
• Who do you want to spend time with?
• What are some great things about you?
• What are your favorite things?
• What things don’t you like?
• What are your hopes and dreams for the future?

Person-centered planning must:
• Base choices on your strengths;
• Help you gain access to resources already available in your community or neighborhood;
• Coordinate services around your life rather than around the needs of staff;
• Recognize the abilities of friends and families to assist you in achieving your dreams;
• Recognize that despite your disabilities, you are the most important person in planning your supports.

Sometimes people need help to make choices because they haven’t had a chance to choose in the past. Your worker can explain your choices and help you try out things that you have not experienced in the past. They must also help you with any difficulties you may have communicating your choices. This can include helping you by being your voice if you are unable to speak, helping others to identify what makes you happy, and making sure that any personal or cultural preferences you have are included in your plan. The worker should also help others communicate with you.

The worker is required to help you figure out the right steps to reach your goals and to make sure that your health and safety needs are met. Our choices are influenced by the resources we have. We may want to live in the biggest house on the block or travel throughout the country. Usually, we have to work up to big plans a step at a time. The important thing is that we are moving in the right direction.

Sometimes you may not always see things that might be a problem for your health and safety, such as: medical conditions, places where you go, or behaviors that you do that may cause harm to you or others. It is your worker’s job to help you identify those areas and to make a plan so that you are healthy and safe. Sometimes unsafe behaviors require the use of a behavior plan or medications. A behavior plan is nothing more than a structured way to help teach you skills that will allow you to be safe and successful. You will be given many chances to practice new behaviors and to get feedback. Medications can be used if you need additional assistance in learning how to control your behavior. Some medications may help you think before you act. If you also have a mental health problem, you may receive medications for that condition.

Person-centered planning is not a one-time thing that happens once per year. Your life changes every day. You meet new people, move to new places, change your goals for the future, develop new support systems, and find new resources in the community that can assist you, or discover new interests. These changes must be included in your person-centered plan as they come up. Your worker will help you arrange another meeting to make changes in the plan. They will make sure that these changes are communicated to others who are important to you.
The best way for you to stay connected is by using the resources that are available to you in your community. This can mean living where you want, shopping at your local store, attending your local church, being involved in community groups, and having a network of friends to do things with. Sometimes you may need additional support to help you be able to do these things better. The developmental disability agency will assist you in finding resources that are able to help you. When there are no resources available, the agency may provide those necessary supports through one of its providers.

PBH is concerned about the impermanence of funding sources and services for individuals with developmental disabilities. We are committed to empowering consumers and their families by giving you the information, skills, and resources you need to identify and obtain the best available supports. In this way, we help you become less reliant on the service delivery system to achieve your goals.

Here are some areas where you may need additional assistance:

**Self-Direction**

Self-direction means increasing your ability to make your own decisions about your life. Some of the supports that may be offered to help you in this area include:

- Opportunities to make your own choices and then to get those things you ask for.
- Practice identifying what is important about a particular choice and how to prioritize what is most important.
- Help in identifying problems with certain choices.
- Teaching caregivers to support self-direction, including allowing you to learn from mistakes.
- Presenting choices to you in a way that you can understand, including through pictures.

**Health Management**

Health management means supporting you to take care of your own health needs to the best of your ability. Some of the supports that may be offered to help you in this area include:

- Giving you information about your health and healthcare.
- Advocating on your behalf with healthcare providers.
- Providing you support when you have a healthcare procedure. This may include preparing you for the procedure by telling you what to expect and teaching you how to relax when you are nervous.
- Managing your healthcare for you if you need this. This can include giving you medication, helping you to prevent problems, providing good nutrition, and identifying times when you may have a health problem.

**Safety Management**

Safety management means helping you identify times when you or others may be in danger. Some of the supports that may be offered to help you in this area include:

- Changing your environment so that you may be safer.
- Providing sex education so that you know what behavior is appropriate at what times.
• Identifying safety needs for you.
• Providing fire safety training and community safety training.
• Providing education so that you know if you are at risk of becoming a victim of abuse or neglect.
• Giving you skills so that you are not alone with strangers.
• Using role-play and pictures to help teach you how to respond to unsafe situations.
• Teaching you how to use emergency numbers.
• Teaching you vehicle safety.
• Teaching you how to not accept items from strangers, including food and pills.

Social Skills

Social skills are ways that you interact with other people to make your needs and wants known. Some of the supports that may be offered to help you in this area include:

• Helping you identify areas where you might like to improve social skills.
• Giving you lots of chances to practice social skills in places where you are comfortable.
• Giving you feedback and reinforcement.
• Breaking skills down into smaller, easier to learn steps.
• Assisting you in practicing skills in the community.
• Providing education to family and friends in ways to assist you in learning new skills.
• Teaching you better ways to express negative emotions.

Self-Care

Self-care involves taking care of your day-to-day needs like bathing, eating, using the bathroom and taking medications. Some of the supports that may be offered to help you in this area include:

• Modifying your home to make it easier for you to take care of yourself.
• Providing items like special spoons or other equipment to make it easier for you to take care of yourself.
• Teaching staff how to do specific things to help you that might be prescribed by a doctor, such as the use of a feeding tube.
• Providing total assistance if you need this for self-care.
• Providing reminders and prompts for those things you can do yourself.

Home Living

Home living means assisting you with the supports to live as independently as possible. Some of the supports that may be offered to help you in this area include:

• Assisting you in choosing where you want to live and the type of housing.
• Making modifications, as needed, to the environment so that you have better mobility.
• Assisting you with other community resources such as a personal response system.
• Assisting you in living with whom you want.

Community Use

Community use means assisting you in increasing your involvement with the community. Some of the supports that may be offered to help you in this area include:
- Assisting you with activities that involve people without disabilities.
- Teaching you how to interact with community people such as a bank teller or a grocery store clerk.
- Teaching you what common signs mean, such as restroom signs.
- Helping you to obtain an identification card.
- Assisting you with skills to use public transportation.
- Helping you to learn street safety.

**Functional Academics**

Functional academics are skills you learn that assist you with daily living, such as how to make change or read a grocery list. Some of the supports that may be offered to help you in this area include:

- Giving you opportunities for enough practice so you can learn a skill.
- Giving you chances to practice the skill in the community.
- Helping you obtain special equipment, if needed, for help in these areas.

**Employment**

Supported employment is a service to help you get a job and provide you with support to be successful in a job. Some of the supports that may be offered to help you in this area include:

- Assisting you in finding a job that matches your skills and desires.
- Breaking down the job into small steps to help you more easily learn the job.
- Assisting you in getting special equipment that will help you with the job.
- Helping you identify your strengths for a particular job.
- Describing, for you and the employer, the specific strengths that you have.
- Helping you with resumes and interview preparation.
- Helping you problem solve if you are having trouble with a job. Talking to your employer to find other ways to assist you if you are having trouble.
- Helping you with transportation to and from the job.
- Job follow-up as needed to see how you are doing.

**Leisure Skills**

Leisure skills are activities that you find enjoyable that may be done with other people. Some of the supports that may be offered to help you in this area include:

- Helping you make choices about what leisure activities you want to do.
- Helping you with planning when your interests in leisure activities change.
- Assisting you with needed transportation so you can do the leisure activities that you want to do.
- Helping you with special equipment that you may need so you can participate in desired activities.
- Ensuring that any items you use, such as bicycles, are in good working order.
- Offering opportunities to participate with non-disabled people.
- Assisting you in building relationships with other people.
APPENDIX A

Montreal Declaration on Intellectual Disabilities

THE MONTREAL DECLARATION ON INTELLECTUAL DISABILITIES

AFFIRMING that persons with intellectual disabilities, as other human beings, are entitled to basic human rights and fundamental freedoms, as embedded in many existing international declarations, conventions, and standards;

EXHORTING the members of the Organization of American States (OAS) to make effective the provisions of the Inter-American Convention on Elimination of All Forms of Discrimination against Persons with Disabilities;

DESIRING to address the historical disadvantages and barriers facing persons with intellectual disabilities and mindful of the need to alleviate the negative impact of poverty on their conditions of life;

MINDFUL that persons with intellectual disabilities have often been excluded from decisions about their human rights, health and well-being, and that guardianship laws have historically been used to deny persons with intellectual disabilities their right to make decisions;

CONCERNED that the freedom of persons with intellectual disabilities to make their own choices has frequently been unrecognized, ignored, abused or removed;

SUPPORTING the mandate of the United Nations Ad Hoc Committee to prepare a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities;

ACKNOWLEDGING the importance of a human rights approach to health, wellbeing and disability;

RECOGNIZING the needs of persons with intellectual disabilities and their aspirations to be fully included and valued as equal citizens, as established in the Declaration of Managua (1993); and

MINDFUL of the significant importance of international cooperation in order to promote better conditions for the exercise and full enjoyment of human rights and fundamental freedoms of persons with intellectual disabilities;

WE, Persons with intellectual and other disabilities, families, representatives of persons with intellectual disabilities, intellectual disability specialists, health specialists and other specialists from the disability field, State representatives, services providers and managers, advocates, legislators and lawyers, assembled at the Montreal PAHO/WHO International Conference on Intellectual Disability, held on October 5th and 6th 2004, together

DECLARE THAT

1. Persons with intellectual disabilities, as other human beings, are born free and equal in dignity and rights.
2. Like all other human characteristics, intellectual disabilities are an integral part of the human experience and diversity. Intellectual disabilities are understood differently by cultures, and thus require the international community to respect its universal values of dignity, self-determination, equality and justice for all.

3. States have the obligation to protect, fulfill and ensure that all civil, political, economic, social and cultural rights, and fundamental freedoms of persons with intellectual disabilities are exercised in accordance with national laws, and international human rights conventions, declarations and standards. States therefore have the obligation to protect persons with intellectual disabilities against medical or scientific experimentation without their knowledgeable and unconstrained consent, or any form of violence, abuse, discrimination, segregation, stigmatization, exploitation, cruel, inhuman or degrading treatment or punishment.

4. Human rights are indivisible, universal, interdependent and inter-connected. Therefore, the right to the highest possible level of physical and mental health and well being is inter-connected with other civil, political, economic, social, and cultural rights and fundamental freedoms. For persons with intellectual disabilities, as for other persons, the exercise of the right to health requires full social inclusion, an adequate standard of living, access to inclusive education, access to work justly compensated and access to community services.

5. a) All persons with intellectual disabilities are full citizens, equal before and under the law, entitled to exercise their rights on the basis of respect of their differences and of their individual choices;

b) The right to equality for persons with intellectual disabilities is thus not only of opportunity, but may also require, when they chose so, appropriate measures, positive actions, accommodations and supports. States must guarantee the presence, the availability, the access and the enjoyment of adequate services based on the needs and the free and informed consent of persons with intellectual disabilities;

c) The respect of human rights and fundamental freedoms of persons with intellectual disabilities requires their full community inclusion. As such, all persons with intellectual disabilities must have access to education, training and information with regard to their rights and obligations.

6. a) Persons with intellectual disabilities have the same right as other people to make decisions about their own lives. Even persons who have difficulty making choices, formulating decisions and communicating their preferences can make positive choices and decisions that further their personal development, relationships and participation in their communities. Consistent with the duty to accommodate in paragraph 5b, persons with intellectual disabilities should be supported to make their choices and decisions, to communicate them and to have them respected. Accordingly, where individuals have difficulty making independent choices and decisions, laws and policies should promote and recognize supported decision-making. States should provide the services and the necessary support to facilitate persons with intellectual disabilities in making meaningful decisions about their own lives;

b) Under no circumstance should an individual with an intellectual disability be considered completely incompetent to make decisions because of his or her disability. It is only under the most extraordinary of circumstances that the legal right of persons with intellectual disabilities to make their own decisions can be lawfully interrupted. Any such interruption can only be for a limited period of time, subject to periodic review, and pertaining only to those specific decisions for which the individual has been found by an independent and competent authority to lack legal capacity;
c) That independent and competent authority must find by clear and convincing evidence that, even with adequate and appropriate supports, all less restrictive alternatives to the appointment of a surrogate decision-maker have been exhausted. That authority must be guided by due process, including the individual’s right to: notice; be heard; present evidence; identify experts to testify on his or her behalf; be represented by one or more well-informed individuals who he or she trusts and chooses; challenge any evidence at the hearing; and appeal any adverse finding to a higher court. Any surrogate decision-maker must take account of the person’s preferences and strive to make the decision that the person with an intellectual disability would make if he or she were able to do so.

To this end, WE, the participants at the Montreal PAHO/WHO Conference on Intellectual Disability, in solidarity of efforts already taken at the national and international levels, do jointly and individually,

AGREE

7. To support and defend the rights of persons with intellectual disabilities; to disseminate the international human rights conventions, declarations and standards that protect the human rights and fundamental freedoms of persons with intellectual disabilities; and to promote, or establish when they do not exist, the integration of these rights into relevant national policies, legislations and plans;

AND

To support, promote and implement actions in the Americas furthering social inclusion and participation of persons with intellectual disabilities through an intersectorial approach involving the persons themselves, their families, their social networks, and their communities.

Accordingly, WE, the participants at the Montreal PAHO/WHO Conference on Intellectual Disability,

CALL UPON

9. THE STATES:

a) To recognize that persons with intellectual disabilities are full citizens in society;

b) To fulfill their obligations, given by national and international laws, to recognize and protect the rights of persons with intellectual disabilities; to ensure their involvement in the development and evaluation of any law, policy or plan concerning them; and to assign the economic and administrative resources required for the effective implementation of those laws;

c) To develop, establish and take the legislative, judicial, administrative and educational means necessary in order to achieve the full social inclusion of persons with intellectual disabilities;

d) To provide to communities and to persons with intellectual disabilities and their families the support needed for the exercise of their rights; promoting and strengthening their organizations;

e) To develop and implement human rights education, training and information programs to persons with intellectual disabilities.
10. VARIOUS SOCIAL AND CIVIL ACTORS:
a) To become actively involved in the respect, promotion and protection of the human rights and fundamental freedoms of persons with intellectual disabilities;

b) To vigilantly protect their dignity and physical, moral and psychological integrity by the creation and maintenance of social conditions of openness and non-stigmatization.

11. PERSONS WITH INTELLECTUAL DISABILITIES AND THEIR FAMILIES:
a) To be aware that they share the same rights and freedoms as all other human beings; that they are entitled to due process of law and that ultimately they have the right to a legal recourse or any other effective recourse to a competent court or tribunal for protection against acts that violate their fundamental rights recognized by national and international laws;

b) To make sure that they are involved in the development of all national legislation, policy and plan that concerns them, as well as their ongoing evaluation;

c) To work in collaboration with national and international, governmental and/or non-governmental disability organizations in order to mutually consolidate and reinforce themselves at the national and international level for the active promotion and defence of the fundamental rights of persons with a disability.

12. INTERNATIONAL ORGANIZATIONS:
a) To integrate “intellectual disabilities” in their classifications, programs, areas of work, and initiatives, in reference to “persons with intellectual disabilities” and their families in order to ensure the full exercise of their rights and determine the specific guidelines and actions in this area;

b) To collaborate with States, persons with intellectual disabilities, family members, and non-governmental organizations representing them, to dedicate resources and technical assistance to promote the goals of the Montreal declaration on intellectual disabilities, including support for full participation in society of persons with intellectual disabilities and integrated models of community services.

The following individuals have signed, in Montreal, Canada, on October 6th 2004, the Montreal Declaration on intellectual disabilities

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Appendix B

Statement on the Right to Effective Behavioral Treatment, 1989

The Association for Behavior Analysis issues the following position statement on clients’ right to effective behavioral treatment as a set of guiding principles to protect individual from harm as a result of either the lack or the inappropriate use of behavioral treatment.

The Association for Behavior Analysis, through majority vote of its members, declares that individuals who receive behavioral treatment have a right to:

1. A therapeutic physical and social environment: Characteristics of such an environment include but are not limited to: an acceptable standard of living, opportunities for stimulation and training, therapeutic social interaction, and freedom from undue physical or social restriction.

2. Services whose overriding goal is personal welfare: The client participates, either directly or through authorized proxy, in the development and implementation of treatment programs. In cases where withholding or implementing treatment involves potential risk and the client does not have the capacity to provide consent, individual welfare is protected through two mechanisms: Peer Review Committees, imposing professional standards, determine the clinical propriety of treatment programs; Human Rights Committees, imposing community standards, determine the acceptability of treatment programs and the degree to which they may compromise an individual’s rights.

3. Treatment by a competent behavior analyst: The behavior analyst’s training reflects appropriate academic preparation, including knowledge of behavioral principles, methods of assessment and treatment, research methodology, and professional ethics; as well as practical experience. In cases where a problem or treatment is complex or may pose risk, direct involvement by a doctoral-level behavior analyst is necessary.

4. Programs that teach functional skills: Improvement in functioning requires the acquisition of adaptive behaviors that will increase independence, as well as the elimination of behaviors that are dangerous or that in some other way serve as barriers to independence.

5. Behavioral assessment and ongoing evaluation: Pretreatment assessment, including both interviews and measures of behavior, attempts to identify factors relevant to behavioral maintenance and treatment. The continued use of objective behavioral measurement documents response to treatment.

6. The most effective treatment procedures available: An individual is entitled to effective and scientifically validated treatment; in turn, the behavior analyst has an obligation to use only those procedures demonstrated by research to be effective. Decisions on the use of potentially restrictive treatment are based on consideration of its absolute and relative level of restrictiveness, the amount of
time required to produce a clinically significant outcome, and the consequences that would result from delayed intervention.

This statement was developed by the Association for Behavior Analysis Task Force on the Right to Effective Behavioral Treatment [members: Ron Van Houten (Chair), Saul Axelrod, Jon S. Bailey, Judith E. Favell, Richard M. Foxx, Brian A. Iwata, and O. Ivar Lovaas]. This Position Statement was accepted by the ABA Executive Council in October 1987 and by the ABA membership in 1989.
Appendix C

Revised Guidelines for Consumers of Applied Behavior Analysis Services to Individuals with Autism and Related Disorders

Autism Special Interest Group (SIG)

DISCLAIMER: This document suggests guidelines for consumers to use in considering who may be qualified to direct applied behavior analysis programs for individuals with autism, as recommended by the Autism Special Interest Group of the Association for Behavior Analysis International. The Executive Council supports the intent of these guidelines; however, it does not represent the official policy or position of the membership of the Association for Behavior Analysis International.

Revision Adopted September 15, 2004

Original Version Adopted May 23, 1998

The Autism Special Interest Group (SIG) of the Association for Behavior Analysis asserts that all children and adults with autism and related disorders have the right to effective education and treatment based on the best available scientific evidence. Research has clearly documented the effectiveness of applied behavior analysis (ABA) methods in the education and treatment of people with autism (e.g., Matson et al., 1996; Smith, 1996; New York Department of Health, 1999; U.S. Surgeon General, 1999).

Planning, directing, and monitoring effective ABA programs for individuals with autism requires specific competencies. Individuals with autism, their families, and other consumers have the right to know whether persons who claim to be qualified to direct ABA programs actually have the necessary competencies. All consumers also have the right to hold those individuals accountable for providing quality services (e.g., to ask them to show how they use objective data to plan, implement, and evaluate the effectiveness of the interventions they use). Because of the diversity of needs of individuals in the autism spectrum and the array of specific competencies amongst the pool of potential service providers, consumers also need to focus on the match between their needs and the specific competencies of a particular provider.

Formal credentialing of professional behavior analysts through the Behavior Analyst Certification Board (BACB) can provide some safeguards for consumers, including a means of screening potential providers, and some recourse if incompetent or unethical practices are encountered. Unfortunately, there continues to exist a tremendous gap between the supply of qualified behavior analysts and the demand for ABA services. Nonetheless, as with any other credentialed professionals, consumers should exercise caution when working with individuals who have, or claim to have, credentials in behavior analysis. Although a formal credential in behavior analysis is evidence that a professional has met minimum competency standards, it does not guarantee that the individual has specific expertise in
autism, nor that s/he can produce optimal treatment outcomes. Furthermore, the credentialing of professional behavior analysts has only been in place on an international level since 2000 and there may be some competent service providers who are still in the process of applying for BACB certification.

The Autism SIG recommends that consumers seek to determine if those who claim to be qualified to direct ABA programs for people with autism meet the following minimum standards:

I. Certification by the Behavior Analyst Certification Board as a Board Certified Behavior Analyst (BCBA), or documented evidence of equivalent education, professional training, and supervised experience in applied behavior analysis. Standards for certification as a BCBA, which can be found at www.BACB.com (Consumer Information Section), include: at least a master's degree in behavior analysis or a related area; 225 hours of graduate level coursework in specific behavior analytic content areas (as of the deadline for Spring 2005 applications); 18 months of mentored experience or 9 months of supervised experience in designing and implementing applied behavior analysis interventions; and a passing score on a standardized examination. Consumers are urged to check the BACB website as these requirements may change from time to time. An individual's BACB certification status may be verified by going to www.BACB.com, clicking on "Consumer Information," and then clicking "Registry."

Note that there is also a lower level of BACB certification, Board Certified Associate Behavior Analyst (BCABA), for individuals who have a bachelor's degree, 135 hours of classroom instruction in behavior analysis (effective for Spring 2005 applications), 12 months of mentored experience or 6 months of supervised experience in implementing applied behavior analysis interventions, and a passing score on a standardized examination.

A complete list of skills and knowledge covered on the Behavior Analyst Certification Board examinations is available at www.BACB.com. Both BCBAs and BCABAs must renew their BACB certification annually, participate in continuing education activities that must meet BACB standards, and adhere to the BACB’s Guidelines for Responsible Conduct (also available at www.BACB.com).

With respect to BCABAs, the Behavior Analyst Certification Board explicitly states that

The BCABA designs and oversees interventions in familiar cases (e.g., similar to those encountered during their training) that are consistent with the dimensions of applied behavior analysis. The BCABA obtains technical direction from a BCBA for unfamiliar situations. The BCABA is able to teach others to carry out interventions once the BCABA has demonstrated competency with the procedures involved under the direct supervision of a BCBA. The BCABA may assist a BCBA with the design and delivery of
introductory level instruction in behavior analysis. It is strongly recommended that the BCABA practice under the supervision of a BCBA, and that those governmental entities regulating BCABAs require this supervision.

The Autism SIG does not consider BCABAs, or individuals with equivalent or less training and experience, to be qualified to independently design, direct, and guide behavior analytic programming for individuals with autism. They may deliver behavior analytic intervention, and may assist with program design, but should be adequately supervised by BCBAs or the equivalent. The Autism Special Interest Group encourages consumers to request the name and contact information of the BCABA's supervisor and check to see that the supervisor is a BCBA or equivalent, as well as the information about the amount and type of supervision he/she provides.

The Autism SIG asserts that certification as a BCBA or documented equivalent training and experience is a necessary but not sufficient qualification to direct programming for individuals with autism. Consumers should be aware that the discipline of applied behavior analysis is broad and varied, and that many individuals who hold certification as a BCBA have little to no experience directing or delivering ABA programming to individuals with autism. Therefore, the Autism SIG considers the following training and experience, in addition to certification as a BCBA or the equivalent, to be necessary to competently direct ABA programming for individuals with autism:

IIa. At least one full calendar year (full-time equivalent of 1000 clock hours [25 hrs/wk for 40 weeks]) of hands-on training in providing ABA services directly to children and/or adults with autism under the supervision of a Board Certified Behavior Analyst or the equivalent with at least 5 years of experience in ABA programming for individuals with autism. The training and supervision should assure competency in the following areas:

1. ABA programming for individuals with autism. The experience should involve designing and implementing individualized programs to build skills and promote independent functioning in each of the following areas: "learning to learn" (e.g., observing, listening, following instructions, imitating); communication (vocal and nonvocal); social interaction; self-care; school readiness; academics; self-preservation; motor; play and leisure; community living; self-monitoring; and pre-vocational and vocational skills.

2. Providing ABA programming to at least 8 individuals with autism spectrum disorders who represent a range of repertoires and ages.

3. Employing an array of scientifically validated behavior analytic teaching procedures, including (but not limited to) discrete trial instruction, modeling, incidental teaching and other "naturalistic" teaching methods, small group instruction, activity-embedded instruction, task analysis, and chaining.
4. Incorporating the following techniques into skill-building programs: prompting; error correction; reinforcement and manipulation of motivational variables; stimulus control (including discrimination training); preference assessments; and choice procedures.

5. Employing a wide array of strategies to program for and assess both skill acquisition and skill generalization.

6. Modifying instructional programs based on frequent, systematic evaluation of direct observational data.

7. Conducting functional assessments (including functional analyses) of challenging behavior and becoming familiar with the array of considerations that would indicate certain assessment methods over others.

8. Designing and implementing programs to reduce stereotypic, disruptive, and destructive behavior based on systematic analysis of the variables that cause and maintain the behavior and matching treatment to the determined function(s) of the behavior.

9. Incorporating differential reinforcement of appropriate alternative responses into behavior reduction programs and efforts to teach replacement skills, based on the best available research evidence.

10. Modifying behavior reduction programs based on frequent, systematic evaluation of direct observational data.

11. Providing training in ABA methods and other support services to the families of at least 8 individuals with autism.

12. Providing training and supervision to at least 5 professionals, paraprofessionals, or college students providing ABA services to individuals with autism.

13. Collaborating effectively with professionals from other disciplines and with family members to promote consistent intervention and to maximize outcomes.

IIb. Additional training in directing and supervising ABA programs for individuals with autism that involves:

- Formal training and/or self-study to develop knowledge of the best available scientific evidence about the characteristics of autism and related disorders, and implications of those characteristics for designing and implementing educational and treatment programs, including their impact on family and community life.

- Formal training and/or self-study to develop knowledge of at least one curriculum for learners with autism consisting of: (a) a scope and sequence of skills based on normal developmental milestones, broken down into component skills based on research on teaching individuals with autism and related disorders; (b) prototype programs for teaching each skill in the curriculum, using behavior analytic methods; (c) data recording and tracking systems; and (d) accompanying materials.

- Formal training and/or self-study to develop skills in using scientifically validated methods to assess and build vocal-verbal and nonverbal communication repertoires in
people with autism, consistent with the principles and practices of behavior analysis. This includes augmentative and alternative communication systems for individuals with limited vocal repertoires that are matched to the individual needs of the learner.

- Accrual of continuing education in the best available research from behavior analysis and other scientific disciplines as it informs autism treatment. The Autism SIG encourages consumers to ask prospective directors of ABA services for evidence that they have participated recently in continuing education activities relevant to the treatment of individuals with autism like those they will be serving (e.g., preschoolers, adults, individuals with limited vocal-verbal repertoires, etc.).

The Autism SIG urges consumers to ask prospective directors of ABA services (including those who use titles such as "consultant") to provide evidence of their qualifications in the form of:

- Certification as a Board Certified Behavior Analyst (BCBA), or documented equivalent qualifications;
- Information about the amount and type of supervision they provide to all those who deliver intervention directly to individuals with autism and monitoring of the level of involvement/responsibilities and certification status of their supervisees (i.e., BCABAs are not qualified to independently design, direct, and oversee programming);
- Membership in the Association for Behavior Analysis International (ABA International);
- Membership in an affiliated chapter of ABA International (e.g., CalABA, NYSABA, TxABA, FABA, NJABA);
- Undergraduate, graduate, and post-graduate training in behavior analysis specifically, as differentiated from non-behavior analytic study in psychology, special education, education, or other disciplines;
- Letters of reference from employment supervisors and/or families for whom they have directed ABA programming for similar individuals with autism (with appropriate safeguards taken to ensure privacy and confidentiality); and
- Publications of behavior analytic research in peer-reviewed professional journals.

Consumers should be aware of the following:

1. Attending or giving some workshops, taking some courses, or getting brief hands-on experiences does NOT qualify an individual to practice applied behavior analysis effectively and ethically. Unfortunately, there may be some individuals who misrepresent themselves when describing their skills and experiences to consumers.

2. Evidence of attendance and active participation in professional meetings and conferences in behavior analysis (e.g., the annual meeting of the Association for Behavior Analysis) is certainly desirable. Such activities by themselves, however,
do not constitute training in behavior analysis, and conference presentations are not equivalent to publications in peer-reviewed professional journals because conference presentations typically are not reviewed carefully by a number of other behavior analysts, and do not have to meet scientific standards. Therefore, it is important for consumers to differentiate presentations at conferences and workshops from publications in peer-reviewed journals.

3. Consumers who have concerns about the ethical behavior of individuals providing ABA services are strongly encouraged to contact the Behavior Analyst Certification Board in the case of a BCBA or BCABA, and discipline-specific licensing boards in the case of those holding professional licensure (such as psychologists, speech-language pathologists, physicians, social workers).

Selected Resources

Behavior Analyst Certification Board - www.BACB.com


U.S. Surgeon General's Report on Mental Health
Appendix D

Questions to ask ABA providers of autism services

**Question:** I’ve run into a number of people who say they supervise ABA programs, but all they have for training is working with one or two children with autism and going to a couple conferences. How do I know if someone is a competent behavior analyst?

The Autism Special Interest Group of the Association for Behavior Analysis has assembled a list of requirements for individuals competent to direct programming (found at [www.abainternational.org](http://www.abainternational.org)). The document is entitled, “Revised Guidelines for Consumers of Applied Behavior Analysis Services to Individuals with Autism and Related Disorders.” An additional resource would be the Behavior Analyst Certification Board at [www.BACB.com](http://www.BACB.com). Certification is not, however, equivalent with experience in Early Intensive Behavioral Intervention nor autism in general. Below is one other list of questions to ask a behavior consultant and the kinds of answers you would expect to hear.

1) **What experience do you have in the field of Applied Behavior Analysis?**

**IMPORTANCE:** Supervising an early intervention program is not a skill that can be taught in the classroom, let alone be mastered at a conference or in-service. A “behavior consultant” with little to no experience is like a dance instructor who doesn’t really dance or a piano teacher that can barely play the piano. Because implementing a program based in Applied Behavior Analysis relies on training people to DO something and not simply understand something, there is no greater question than a person’s previous experience in the field. Ask yourself, would you hire a physical fitness trainer who wasn’t physically fit? Below are more detailed questions to find out how “physically fit” a behavior consultant might be.

A) **How many years of experience did you have as an instructor before becoming a behavior consultant?**

Lovaas Institute personnel generally have a minimum of 2 years, full time experience as an instructor before they are considered as a candidate for consultant training. Because the therapy is complex and many faceted, it requires a high level of expertise with a significant level of training and supervision. Lovaas Institute personnel make regular clinical judgments on a minute-by-minute basis, rather than following a stale written plan. Field experience emphasizes a system which delivers high-quality decision making. Lovaas Institute personnel use complicated information and analysis to make the best choices for the short term and for the long term. These considerations bear on the child’s therapy.

B) **What types of children did you work with as an instructor?**

Autism is a spectrum disorder. Different children require emphasis on different skills and different techniques. Returning to the analogy, a person who knows how to dance the mambo still needs to learn how to dance the tango. Lovaas Institute personnel are active with children across the spectrum before completing training as a consultant. In this way, they are familiar with effective techniques, no matter how a child “dances.”

C) **Who oversaw your work as an instructor?**

Lovaas Institute personnel receive feedback on a weekly basis from qualified behavior consultants while working with clients and participating in team meetings at the Institute.

D) **How were you trained to be a behavior consultant?**

The Lovaas Institute uses a pyramid training approach that has a lengthy and well-regarded history in the field of community psychology. This systematic approach allows personnel to gradually take on more responsibility as an instructor, followed by specific training and formal competencies related to a consultant’s role. This training includes: passing academic tests on Applied Behavior Analysis and the Lovaas model methodology, designing and defending
interventions based on observations of different children, shadowing of current behavior consultants, and responding to hypothetical situations under the guidance of other consultants and the site supervisor.

E) How many years of experience do you have and who oversees you now?

The Lovaas Institute continues to assure quality control through oversight of all behavior consultants. Reports and programming for each child are submitted to the Institute for review. The Lovaas Institute holds meetings to discuss ongoing research affecting best practices. And, Lovaas Institute consultants participate in a private email list with other consultants, program directors, and psychologists that specialize in the treatment of children with autism throughout the world.

2) What is your academic background in the field of Applied Behavior Analysis?

IMPORTANCE: While experience in the field under qualified supervision is the most important factor in finding a behavior consultant, every behavior consultant should have the academic background to evaluate interventions effectively and speak intelligently not only to parents, but also to others in the field. Basic questions to ask include:

A) What’s the educational background of the team providing consultation and supervision/consultation oversight?

With the Lovaas Institute, you aren’t simply assigned a behavior consultant. You receive support from a behavior therapy team. While educational background varies, typically the team includes Board Certified Behavior Analysts, higher degrees in Applied Behavior Analysis, and master’s level work in psychology, education, speech-language pathology, etc.

B) What credentials or licensing does the agency hold?

Individual certification such as the national BCBA credential is a new phenomenon in the field of Applied Behavior Analysis. For more detailed information on a company or organization, its past credentials and licensing should also be asked for.

3) How flexible is your approach?

IMPORTANCE: A good program based in Applied Behavior Analysis recognizes the ongoing progress made in our understanding of human behavior from published research. A good program based in Applied Behavior Analysis also recognizes the difference between theory and practice, and that no single approach is effective for everyone. The following questions can help determine how well a behavior consultant balances these issues.

A) How do you stay current with ongoing research in the field of Applied Behavior Analysis?

B) What are some examples of how what you do with most children you may not do in a particular circumstance?

C) How do you determine what the best approach to take is?

D) How do you handle situations where a family wants to include other interventions besides ABA?
Appendix E: Writing an Effective Behavior Support Plan

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Behavior plans are written for many purposes. The following checklist is intended to help develop and revise plans for adults with developmental disabilities. The behavior plan may be part of a broad "adult service plan," or it may stand alone as a plan to manage one problem behavior. The written plan is an essential component of an individual's service, because it provides a clear guide for service providers and assures consistent, caring, and effective services.

- **Individualized.** It is essential that the plan be written for the individual, not for a program. Plans should be preceded by a comprehensive individualized functional behavior assessment of all target behaviors. If all written plans are the same for every person in a program, the individual's service needs have not been considered.

- **Clear.** Is the Individualized Behavior Support Plan written in a manner that can be understood and followed by every staff member? Can family members, guardians, auditors, and other concerned parties understand it? Does it have undefined abbreviations (e.g., ITO, PIC, DRO) or jargon that cannot be understood by interested non-professionals? If a procedure is described (e.g., ignore the problem behavior), does everyone understand exactly what is to be done and under what conditions?

- **Person-centered.** Has the individual participated in the design of the behavior plan? Does the individual understand the behavior plan?

- **Emphasis on prevention.** The plan should note aspects of the program that are preventive and routinely available. Use of such elements typically does not require a written behavior plan, but stating them helps to assure the reader that customary preventive steps are being taken. Examples: Use of schedules and other forms of environmental structure to make the routine clear, efforts to enrich the environment (frequent access to reinforcers), diversity of activities, antecedent changes.

- **Choice.** Does the plan reflect the individual's preferences and provide meaningful opportunity to chose activities and reinforcers? If the individual does not know how to make a meaningful choice, does the program offer an opportunity to learn? (Use of choice should also contribute to prevention.)

- **Positive emphasis.** The plan should place greater emphasis on the development of adaptive behavior than on the reduction of problem behavior. The plan should ALWAYS respect individual rights and avoid all aversive measures.

- **Punishment or rights restriction specified.** Punishing consequences or restrictions of rights should not be used unless justified by prior attempts to manage the behavior in a positive way. In the unusual circumstance that punishment has been approved for use or approval is being requested, the punishing (aversive) consequence must be clearly specified. If rights are restricted, specify a criterion for restoring rights and a plan to achieve that criterion.

- **Quality assurance.** The program should be reviewed at specified intervals. Formal review may not be required if no punishment or rights restriction is involved. The date of the next review should be stated.

- **Staff implementation.** A common reason that behavior programs do not work is that they are not implemented as planned. Are there factors in the plan that make it difficult or unappealing for staff members to implement? Are there reinforcers for the staff for implementation, or does the behavior program place unreasonable burdens on the staff?
ELEMENTS TO INCLUDE IN THE
INDIVIDUALIZED BEHAVIOR SUPPORT PLAN

1. **Current information.** Nature of residence, work or day activities, staffing and other available resources should be noted.

2. **Background.** The written plan should include summary information on the individual that is helpful in understanding his/her disability, past and current medication, extent to which the individual has been able to engage in productive work, domestic life, and self-care, extent to which problem behavior has limited opportunities for satisfying adult living.

3. **Problem behavior defined.** Is the problem behavior described in terms that allow it to be measured objectively? Whether the goal is to increase adaptive behavior, decrease problem behavior, or both, the problem behavior must be observable and measurable.

4. **Summary of functional behavior assessment.** A comprehensive functional assessment of problem behavior should allow the development of reasonable hypotheses about the function of the problem behavior. The plan should state the function of the problem behavior (e.g., positive reinforcement through attention from staff, negative reinforcement through escape from demands, automatic positive reinforcement through sensory consequences, etc.). Subsequent plans should state whether the data support the functional assessment or whether the hypotheses should be changed.

5. **Context described.** Is information provided about the context in which the behavior that is targeted for change occurs (e.g., activities, places, times, persons present, etc.)? These are often referred to as the antecedents of the behavior (or setting events or establishing operations). Some problems occur only in the morning, in the presence of certain staff members, when demands are made, when crowded, etc.

6. **Measurable objectives.** The objective or desired outcome of treatment should be stated in clear and measurable terms. For example, the objective may be a low or high rate and/or intensity of a specified behavior. The objective should be stated in positive terms (e.g., increased participation in activities), not exclusively in terms of behavior reduction (e.g., low rate of hitting).

7. **Time limit.** The date or interval of time in which the objective is to be reached should be stated.

8. **Adaptive/alternative behavior defined.** The appropriate/alternative behavior that is to be taught or strengthened must be defined in observable terms. The alternative behavior will replace the problem behavior and serve the same function as the suppressed target behavior.

9. **Reinforcer specified.** The reinforcer used to strengthen the adaptive behavior must be specified. In order to specify an effective reinforcer, it is necessary to know a variety of consequences that are potentially reinforcing for the individual. In other words, it is important to know what he/she likes.

10. **Schedule of reinforcement.** Specify whether the behavior is to be reinforced each time it occurs (continuous reinforcement) or on another, specified schedule.

11. **Baseline data.** A baseline measure of the problem behavior should be reported. The measure should be objective and quantitative, and the time that the baseline lasted should be specified. If the behavior to be reduced is dangerous, and it is important to begin the program as soon as possible, make some estimate of the frequency and severity of the behavior before the program began.

12. **Data on adaptive/alternative behavior.** A method for measuring changes in adaptive behavior over time should be specified. The measure may be one of rate, intensity, percent of occurrence when the
opportunity was present, etc. The times when the behavior will be measured should be specified (e.g., Monday through Friday mornings during breakfast, hourly samples from 9 A.M. to 3 P.M., etc.).

13. **Data on problem/target behavior.** Similar data should be collected on the behavior to be decreased. Collecting data on the individual’s behavior is the only real way of measuring the outcome (effectiveness) of the individualized behavior support plan.

14. **The latest date** at which the individualized behavior support plan and its outcome should be reviewed and plan revised as needed.

15. **Signatures** of individual for whom the plan is written, guardian, support broker, psychologist preparing the plan, other stake-holders.

The above information will not assure that a behavior plan will be effective, but it will help. This information will make communication clearer and will make the implementation of the plan more efficient. To some extent, a clearly written behavior plan also assures that services are offered in an ethical manner. The specification of this information demonstrates respect for the right of the consumer to an effective program and to freedom from problem behavior that may be harmful or that may limit opportunities for greater independence.

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References


Practice Guidelines in DD


