



North Carolina Department of Health and Human Services
Division of Mental Health, Developmental Disabilities and Substance Abuse Services

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December 15, 2003

MEMORANDUM

TO: Consumer/Family Advisory Committee Chairs
Advocacy Organizations and Groups
North Carolina Association of County Commissioners
North Carolina Council of Community Programs
Area Program Directors
Provider Organizations
MH/DD/SAS Professional Organizations and Groups
MH/DD/SAS Stakeholder Organizations
Other MH/DD/SAS Stakeholders

FROM: Steven E. Hairston, Planning Team Leader

RE: **Best Practice in Supports and Services to Individuals with Developmental Disabilities.**

Attached is a draft of *Supporting Individuals and Families in Their Communities; Best Practice in Services and Supports to Individuals with Developmental Disabilities*. This document reflects the continued movement toward reform and evidenced-based practice. It is consistent with the Guiding Principles of the State Plan and establishes a solid framework for implementation of services and supports that promote individuals with developmental disabilities living and participating in communities of their choice.

Please review and offer comments on this draft. Comments will be accepted through the close of the business day on February 16, 2004. Comments may be emailed to me at Steven.Hairston@ncmail.net or mailed to my attention at Steven E. Hairston, Planning Team Leader, 3003 Mail Service Center, Raleigh, North Carolina 27699-3003. In order for comments sent by mail to be considered for inclusion in the final document, they must be received by the close of the business day on February 16, 2004. Thank you for your continued leadership in the reform efforts.

Cc: Secretary Carmen Hooker Odom
Lanier Cansler
James Bernstien
Mark Van Sciver
MH/DD/SAS Staff



Best Practices in Services and Supports for Individuals with Developmental Disabilities

- I. Supporting Individuals and Families in Their Communities
 - A. History
 - B. Quality Framework
 - (1) Access to Services, Supports, and Treatment
 - (2) Person Centered Service Planning
 - (3) Person Centered Service Delivery
 - (4) Provider Capacity and Capabilities
 - (5) Safeguards
 - (6) Individual Rights and Responsibilities
 - (7) Individual Outcomes and Satisfaction
- II. Health-Related Services and Supports
 - A. Discussion
 - B. Best Practice Recommendations
- III. Housing and Residential Supports
 - A. Discussion
 - B. Best Practice System Elements
 - C. Best Practice Related to Supports for Home Living
 - D. Challenges and Barriers to Best Practice
- IV. Employment
 - A. Discussion
 - B. Supported Employment: Values and Philosophy
 - C. Long-Term Follow-up Employment Supports
- V. Social, Community and Leisure
 - A. Social Skills
 - (1) Discussion
 - (2) Specific Challenges
 - (3) Best Practice Related to Supports for Social Skills
 - B. Community Use
 - (1) Discussion
 - (2) Specific Challenges
 - (3) Best Practice Related to Supports for Community Use
 - C. Leisure
 - (1) Discussion
 - (2) Specific Challenges
 - (3) Best Practice Related to Supports for Leisure Skills
 - (4) The Importance of Relationships
- VI. Best Practices Related to Specific Populations
 - A. Autism Spectrum Disorder
 - (1) Basic Descriptions of Disorders

Draft

- (a) Autism
- (b) Asperger's Disorder
- (c) Childhood Disintegrative Disorder
- (d) Other Pervasive Developmental Disorders - Not Otherwise Specified (Atypical Autism)
- (e) Prevalence
- (2) Interventions
 - (a) Applied Behavior Analysis (ABA)
 - (b) TEACCH
 - (c) Auditory Integration Training
 - (d) Facilitated Communication
 - (e) Sensory Integration
- (3) Best Practice Recommendations
- B. Challenging Behaviors
 - (1) Discussion
- C. Co-Occurring Disorders
 - (1) Discussion
 - (2) Assessment
 - (3) Psychosocial Treatment
 - (4) Substance Abuse Issues
 - (5) Medication Treatment
 - (6) Crisis Planning
- D. Medically Involved/Medically Fragile Children
 - (1) Discussion
 - (2) Best Practice in Supports and Treatment
- E. Traumatic Brain Injury
 - (1) Discussion
 - (2) Best Practice in Treatment and Supports

- VII. Self-Determination
 - (1) Discussion
 - (2) Best Practice Elements

- VIII. Bibliography

I. Supporting Individuals and Families in Their Communities

A. History

Any discussion of best practice in developmental disabilities needs to be framed historically. Prior to the 1950's, mental retardation and other forms of developmental disability were seen as pathological conditions, in which treatment was in segregated, medical contexts. During the 1950's a new principle governing the education and treatment of people with cognitive disabilities was originated in Denmark, with the basic idea of making those individuals' lives as "normal" as possible. The idea of "normalization" placed emphasis on integration of individuals with disabilities into the mainstream of society, and on person-hood, citizenship and developmental potential. It gathered support in the United States through the work of Wolf Wolfensberger in the 1970's, who broadened the ideas beyond the educational and residential realms to include all areas of human experience. He discerned that ultimately, integration is only meaningful if it involves social interaction and acceptance. The terms "right to self determination" and the "dignity of risk" were introduced as important facets of the normalization principle in the work of Wolfensberger and others. (Wolfensberger, 1972; Pelka, 1997; O'Brien, 2000)

Strict adherence to the concepts of normalization was criticized because it was seen as discouraging people with cognitive disabilities from socializing among themselves and from forming self-help and political groups, and it used the non-disabled person as the measure of what was "normal" and desirable. However, the concept of normalization played a central role in the de-institutionalization of many people with disabilities and the beginning integration of these individuals into their communities. Through de-institutionalization and community integration, self-advocacy of individuals with cognitive disabilities became possible. In addition, a community of professionals across North America began a discussion in the late 1970's and early 1980's regarding how the principles of normalization could be applied to improve the quality of life for individuals with developmental disabilities. A group of practices known as person-centered planning originated from this dialogue. Person-centered planning still provides a basic means of translating the principles of normalization and self-determination into daily life experience for individuals with disabilities. (Wolfensberger, 1972; Pelka, 1997; O'Brien, 2000)

Self-determination, which implies the ability to control one's circumstances in one's self interest, incorporates the idea of self-direction. Self-direction is the ability of an individual to act as the causal agent in one's life and to make choices within a given set of circumstances. The concept of self-direction has three components, all of which are necessary in order for individuals to act in a self-directed manner. These three components are: (1) an attitude or self view that one is entitled to define one's own goals; (2) the skills and/or accommodations to express preferences, indicate choices and make decisions, and; (3) an environment which supports and promotes these attitudes and skills (Wehmeyer, et.al., 1996). The capacity and ability to exercise self-direction has long been recognized as a value underlying the delivery of services and supports to persons with developmental disabilities.

Consistent with the changes coming from the field of professionals working with people with developmental disabilities, as well as parallel movements in the fields of mental health, aging, and physical disability, the Centers for Medicaid and Medicare Services (then the Health Care

Financing Administration) began realigning its policies toward community integrated services and self-direction. The “institutional bias” in Medicaid policy has been progressively reduced through amendments to federal laws and policy. The Olmstead court decision gave further impetus to this movement in fiscally responsible ways to support individuals in their communities. (Smith, et.al, 2000) The Centers for Medicare and Medicaid Services uses the following values to determine promising practices for home and community based services, giving further support to the principles of community integration, self-determination, and person-centered planning:

- Individuals live in the most integrated community setting appropriate to their individuals support requirements and preferences;
- Individuals exercise meaningful choices about their living environment, their service providers, the types of supports they receive, and the manner in which supportive services are provided; and
- Individuals obtain quality services in a manner consistent with their living preferences and priorities.

B. Quality Framework

Any attempt to review and identify promising practices in regard to individuals with developmental disabilities must begin with a quality framework. In North Carolina the intent of our system must be “To encourage a fundamental approach to the support of persons with disabilities that minimizes reliance on institutions and maximizes community integration in the most cost-effective manner.” (Smith, et.al, 2000)

The following provides a framework for development of a system that supports quality services and supports for individuals with disabilities through focusing on critical dimensions of home and community based service delivery. (National Quality Inventory Project, 2002) The framework was designed through the services of MEDSTAT, the National Association of State Directors of Developmental Disability Services (NASDDDS), National Association of State Units on Aging (NASUA) and the Human Services Research Institute (HSRI) at the request of CMS. It is within this framework that we consider what are best or promising practices for individuals with developmental disabilities and their families. The domain areas and bullet points are largely the work of the National Quality Inventory Project. Some domain areas have been further addressed through the work of The Council on Quality and Leadership in its Personal Outcome Measures or other sources.

(1) Access to Services, Supports and Treatment

Individuals with developmental disabilities and their families often have difficulty in accessing services and supports. Individuals and families must have ready access to services and supports in their communities. (Smith, et.al, 2000) The issue of access is recognized and addressed in State Plan 2003 in chapter 4. A system that supports individuals and families with developmental disabilities must be one in which the triage, screening, and referral process insures that:

- Individuals and families can readily obtain information regarding availability of services, supports, and treatment.

- Intake and eligibility determination processes are understandable and user-friendly. Assistance is available to support the individual and family during the process as needed.
- Individual's and family's needs are assessed and determined promptly.
- Individuals and families are linked to community resources.
- Once services, supports, and treatment are determined they are initiated promptly (Smith, et.al, 2000).
- Service and support criteria need to be consistent and equitably applied across the system.

Informed choice must be based on relevant information, that is concrete and specific enough to enable people to understand the information. Assistance needs to be tailored to the individual needing the information. This includes offering methods conducive to the person's understanding. A description of available services or supports may in itself not be relevant for some individuals. They may have to visit, observe and experience the service or support before making an informed choice. (The Council, 2000). In addition, locations where information is available must be environmentally accessible to individuals who may have physical limitations. Transportation is another limiting factor that should be taken into account in designing a system that is accessible.

Any organization providing services and supports to individuals with developmental disabilities has an obligation to promote coordinated systems of services that are responsive. Linkages must be established with other community resources that offer information, volunteers, supports and services that are outside the immediate purview of the organization. The organization acts as a catalyst to ensure that supports and services are timely, relevant, and customized to meet the individual's needs and personal goals (The Council 2000).

(2) Person Centered Service Planning

Services, supports and treatment to individuals and families should be planned as well as implemented in accordance with each participant's unique needs, expressed preferences and decisions concerning their life in the community. "A system that embraces the principles of person-centered supports engages individuals, their families and allies, and the community organizations in active collaboration to support each individual "one person at a time".... The standard for evaluating developmental disabilities service systems now is the extent to which they embrace and reflect the essential principles of person-centered supports in their day-to-day operations." (Bradley, et.al. 2001) Therefore, the system must be one in which:

- Comprehensive information regarding the individual/family's preferences and personal goals, needs and abilities, health status as well as other available supports is gathered with the individual/family and used in the development of a person centered plan.
- Information and support is available to assist individuals and families to make informed choices regarding service options as well as providers.
- Each individual's plan must comprehensively address his/her identified need for supports, health care and other services in accordance with expressed personal preferences and goals.
- Individuals and families should be supported to direct and manage their own services to the extent they desire. Individuals and families differ in how much involvement they want

in managing services; therefore, consumer directed options within systems operate parallel to the more traditional professionally managed option. (Smith, et.al, 2000)

Self-direction is a component of person-centered planning processes. Research studies indicate that the outcome of services and supports provided are improved when self-direction is explicitly addressed and opportunity for self-expression of choice is provided as part of the planning and service delivery process. Research results generally support the conclusion that even persons with severe and profound disabilities can make choices and that the act of choosing may increase on-task behavior and decrease disruptive behaviors (Lancioni, et.al 1996). Howe, et.al. (1998) found increased community activity participation and social relationships among individuals given choice related to residential services. This does not imply that decisions should never be made on behalf of individuals with developmental disabilities. It does imply that better efforts should be made to improve the abilities of individuals to make choices, to provide training to increase choice making ability and to provide environments where choice-making is the norm and is enhanced. When careful assessment indicates that the individual cannot make certain types of decisions in a reasonable manner, a guardian or other legally empowered person should make these decisions.

Learning about someone's personal goals demands listening and respect. Any organization providing supports and services needs to have strategies for listening and learning about individuals that are adapted to unique communication styles. This might include story telling, drawing and art, photography or video, journals, observing behaviors as well as augmentative communication devices and learning from other people who know the individual best (The Council 2000).

(3) Person Centered Service Delivery

Promising practices continue to reflect a consumer-directed approach with a move away from a medical or professionally managed model. "Over the past few years, as Medicaid's role in furnishing home and community long-term services has expanded, consumer direction and self-management of services have emerged as critical elements in enabling people with all types of disabilities to direct and manage their own services and supports." (Smith, et.al, 2000)

- Individuals and families must have continuous access to assistance as needed to obtain and coordinate services and quickly address issues encountered in community living.
- All services and supports must be provided in accordance with the individual's or family's plan.
- Regular, systematic and objective methods, primarily individual or family feedback, should be used to monitor the individual's well being, health status, and the effectiveness of supports and services in enabling the individual to achieve his/her personal goals.
- Significant changes in the individual or family's circumstances must promptly trigger consideration of modifications to the person-centered plan (Smith, et.al, 2000).

The user of services and supports is the primary customer of the agency, and all aspects of service delivery should be undertaken in this light. Services and supports are methods, and not ends in themselves. Services must be connected with priority outcomes of the individual, and any organization should tailor its services and supports to produce outcomes desired by the consumer (The Council 2000).

(4) Provider Capacity and Capabilities

Any system designed to support individuals with developmental disabilities and their families must have sufficient providers that demonstrate the capability to effectively serve participants:

- There must be sufficient qualified providers to meet the needs of individuals and families in their communities.
- All providers must possess the requisite skills, competencies and qualifications to support individuals and families effectively.
- All providers must demonstrate the ability to provide services and supports in an effective and efficient manner consistent with the individual's or family's plan (Smith, et.al, 2000).

Any organization must define its expectations for staff competency and performance in terms of the ability to facilitate individual achievement of personal outcomes. Employees are evaluated on this basis and there is a clear system for recognition of employee leadership. Personnel development includes strategies for increasing staff competence in listening, facilitation, problem solving and negotiation—all important skills in a system that promotes consumer direction of services and supports. The organization prepares staff to locate community resources, discover resources in neighborhoods, and to network and negotiate with other agencies and businesses. Staff are knowledgeable of personal rights and protections and use of positive approaches. Staff promotes natural support networks and use of generic community resources. They are skilled at emphasizing and promoting each individual's capabilities and aggressively support the individual's pursuit of personal outcomes. Staff understands the true purpose of their work and finds value and commitment in facilitating outcomes that have real meaning in peoples' lives (The Council 2000).

(5) Safeguards

Individuals must be safe and secure in their homes and communities, taking into account their informed and expressed choices:

- Individual risk and safety considerations must be identified with potential interventions considered that promotes independence and safety with the informed involvement of the individual and family.
- There must be systematic safeguards in place to protect individuals from critical incidents and other life-endangering situations.
- The safety and security of the individual's living arrangement should be assessed, risk factors identified and modifications offered to promote independence and safety in the home.
- Behavior interventions, including chemical and physical restraints, must be used only as a last resort and subject to rigorous oversight. In addition, proactive as well as reactive crisis contingency plans must be in place to prevent over reliance on crisis systems.
- Medications must be managed effectively and appropriately.

- Safeguards must be in place to protect and support participants in the event of natural disasters and public emergencies (Smith, et.al, 2000).

Organizations providing services and supports must provide the basic protections to guard personal health, safety and welfare. In addition to addressing individual health and safety issues through person centered planning, organizational policies and procedures must provide basic protections such as preventing and addressing abuse and neglect, screening procedures for staff, meeting fire and building standards, evacuation plans for natural disasters, etc. Organizations also protect income, savings and possessions of individuals. These policies and procedures must be individualized so that they work effectively for each individual and circumstance (The Council 2000).

(6) Individual Rights and Responsibilities

Individuals with developmental disabilities must receive support to exercise their rights as well as accepting their responsibilities.

- Individuals must be informed of and supported to freely exercise their fundamental constitutional and federal or state statutory rights.
- Individuals must receive training and support to exercise and maintain their own decision-making authority.
- Any decisions to seek guardianship, surrogates or other mechanisms that take authority away from individuals must be considered only after a determination is made that no less intrusive measures are or could be available to meet the individual's needs.
- Individuals and families must be informed of and supported to freely exercise any due process rights.
- Individuals and families must be informed of how to register any grievances and complaints and must be supported in seeking resolution. Any grievances or complaints should be resolved in a timely manner (Smith, et.al, 2000).

Organizations assist individuals to exercise rights that will facilitate their priority outcomes. There is a difference between “not denying” rights and “assisting” people to exercise their rights. Staff assists individuals to understand their priority rights through individualized instruction, examples and other methods compatible with each individual's capability to understand and communicate. The organization should have clear due process procedures and provide assistance to individuals to use those procedures (The Council 2000). An individual should be assumed to have all rights unless specifically taken away through legal means.

(7) Individual Outcomes and Satisfaction

Within any system of services and supports individuals must be satisfied with their services and achieve desired outcomes. The system must support individuals efficiently and effectively and continuously strive to improve quality.

- Individuals and family members must express satisfaction with their services and supports.

- Services and supports must lead to positive outcomes for each individual (Smith, et.al, 2000).

Individual outcomes and satisfaction result from listening, respecting and responding to the expressed desires of people being supported. An organization needs to have a process for eliciting and analyzing feedback on services and supports for individuals. Feedback that pertains to individual personal outcomes should be elicited in a way that is compatible with the individual's personal communication style, and should directly influence a person's plan and delivery of supports and services. Individual information is aggregated to analyze and change organizational procedures. There should also be more formal processes such as surveys and questionnaires, focus groups and email, for eliciting feedback regarding the system of services and supports (The Council 2000).

II. Health-Related Services and Supports

A. Discussion

In recent years there has been growing recognition of the importance of health and health promotion for individuals with disabilities. There is evidence that low socioeconomic status, limited access to preventive care and health promotion, and attitudinal, communication and environmental barriers are among the underlying causes. People with developmental disabilities encounter significant structural, financial, and personal barriers that limit their access to health programs and services. Children and adults with developmental disabilities are at risk for developing the same chronic conditions as the rest of the population, including high blood pressure, heart disease, cancer, diabetes, and depression. In some instances, individuals with disabilities may even be at increased risk.

The major findings of the NC Core Indicators Project survey for individuals with developmental disabilities residing in community settings reveal that:

- Access to health care services is a challenge in the community. Dental services and reproductive health services for women are particularly neglected.
- Physical fitness is a significant concern. Nearly one-third of adults with developmental disabilities living in the community reported that they never engage in physical activity of any kind. Inactivity is a risk factor for many chronic conditions, such as heart disease.
- Although obesity was not directly measured, nearly one-third of the participants were concerned about being overweight. Previous research has emphasized significant weight problems in adults with developmental disabilities.
- Increasingly, the lifestyles of adults with developmental disabilities are similar to those of the general population. They are subject to the same behavioral risk factors of alcohol, tobacco use, and substance abuse. While only 5.5% of the community sample reported drinking alcohol, 17.4% reported smoking tobacco. Smoking tobacco is the leading cause of preventable death and leads to an increased risk for heart disease, stroke, lung cancer, and other respiratory diseases.
- Adults with developmental disabilities experience an alarmingly high rate of mental health problems (30.1%). Inadequate levels of social support and high levels of stress contribute to

this increased risk. More than half of adults with developmental disabilities in North Carolina are prescribed one or more psychotropic medication (Nearly 20% were treated with two or more psychiatric medications).

Prevention including self-care and counseling, screening for early detection, appropriate and timely treatment, and early recognition and reduction of known risks is critical for people with developmental disabilities. Much of the health promotion developed for use in the general population can be applied directly to individuals with disabilities. However, in some cases, new strategies will need to be adapted or developed, in particular to address the physical, attitudinal, and educational accessibility of programs and services.

B. Best Practice Recommendations

Today the life expectancy of individuals with developmental disabilities has lengthened considerably. In addition, individuals with developmental disabilities are remaining in their communities and are moving out of the institutions. (US Public Health Service 2002) North Carolina data in regard to individuals currently remaining in our Mental Retardation Centers reveals that 90% of those individuals have a diagnosis of severe or profound mental retardation. Epilepsy and visual impairments are the most common physical disabilities. This data has implications for meeting the healthcare needs of individuals with developmental disabilities within our communities in NC. "The Olmstead decision directly relates to primary care of people with disabilities because it focuses on the obligations of states to keep people with disabilities in community settings by ensuring the availability of services, such as primary health services, necessary to help keep them out of institutions." (Moss, pg 17)

- Use existing NC data, such as from the Core Indicators Project and Behavioral Risk Factor Surveillance System to identify health status, health risks, and health disparities for persons with disability in comparison to the general population (e.g., increased risk for physical inactivity, obesity, poor oral health, and chronic health conditions). These data serve as baseline for monitoring changes over time.
- Support activities that promote access to primary and preventive health care and inclusion in health promotion, physical activity and wellness initiatives. Ensure that health promotion programs for the general population offered in both the community and clinical settings are inclusive and responsive to persons with disabilities.
- Promote accessible community health services. Physical and communication access, adaptive equipment, and program accommodations will enable more individuals with developmental disabilities to participate in health promotion and wellness activities.
- Provide health care staff with information and training in order to provide services that are equitable and accessible to persons with disabilities and comparable to those offered to persons without disabilities. Providers need a greater understanding of the ADA, disability issues, and the principles of universal design.
- Support individuals with disabilities to play an active role in promoting their own health. This includes developing a partnership with a primary health care provider, managing their own health, and making informed lifestyle choices.
- Ensure that individuals with mental retardation/developmental disabilities receive assistance in care coordination and transportation to health care services.

- Ensure that individuals and families receive usable information about available health care in their communities.
- Provide advocacy and/or assistance to individuals with developmental disabilities in interacting with health care providers and promoting responsiveness of health care organization/providers.
- Provide support and interaction with health care providers on behalf of individuals with developmental disabilities.
- Provide support for individuals with developmental disabilities during health care procedures, ranging from education to personal and physical support.
- Recognize that direct support staff and caregivers, including families, play a critical role in enabling individuals with developmental disabilities to access health care services and make healthy lifestyle choices.
- Acknowledge the interconnectedness of health to other life domains, such as work, education, recreation, relationships, and community. The principles of self-determination are applicable to health and compatible with person centered planning.

The responsibility for implementation of best practice recommendations challenges traditional roles and practices within the health and disability networks. This approach requires services for persons with developmental disabilities to identify health as a priority outcome. Likewise, it requires the health care system to identify equitable health care for individuals with developmental disabilities as a priority outcome. The mission of public health and primary health care is to ensure that all individuals can access an array of disease prevention and health promotion services, with an emphasis on the needs of undeserved and vulnerable populations. The resources and capacity of the disability community must be partnered with those of the health and public health community in order to address common areas of concern. Collaboration across these sectors is essential in developing integrated systems of care that are person-centered, accessible, and efficient.

III. Housing and Residential Supports

A. Discussion

Best practice in housing for individuals with developmental disabilities, as well as other disabilities, continues to evolve as disability policy shifts from the continuum housing model to the supportive housing approach. (O'Hara, Day 2001). Housing needs are not unique to individuals with developmental disabilities but is an issue confronted by individuals with any disability. Between 1985 and 1996, national institutional populations fell by 45% (Stancliffe & Lakin, 1998) Prior to these changes, many individuals with developmental disabilities spent their entire lives in large institutions or similar congregate settings. Based on the continuum model individuals with the most significant disabilities lived and received services at the most restrictive point on the continuum. These settings tend to be highly segregated and high cost. Those with milder disabilities were served at the least restrictive point, which are the most integrated and are expected to have lower cost. (O'Hara, Day 2001) This continuum model can be seen in our NC system. "It is much more common for North Carolinians with developmental disabilities to be served in relatively large living arrangements than other states. A higher proportion of individuals were served in large, state-run facilities and ICF-MR group homes than nationwide and a significantly lower proportion are supported in living arrangements for 1-3 individuals." (Bradley, et.al, 2001)

In contrast to the continuum model, the model preferred by consumers and the model for which the current evidence of success is the strongest is the supportive housing model linked with a variety of services and supports. (TAC, 2002) “In the support/empowerment paradigm, the “placement” approach to housing (in which professional assessments constitute the main basis for housing selection) is replaced by the principles of consumer choice and control over both housing and supports services. This approach leads to the separation of housing from services and emphasis on normal, integrated, scattered-site housing to reduce stigma and rights of tenancy under landlord/tenant laws. This model also emphasizes that people with significant disabilities-like other extremely low income groups-should have more access to government housing programs to make housing truly affordable, and that scarce resources within systems of care should be spent on expanding community-based services rather than on paying for housing.” (O’Hara, Day, 2001)

Supportive living differs from traditional residential services in several distinct areas. According to Taylor, et.al. (1987), supportive living is described as finding a home that is not agency owned or operated and then providing the flexible supports that people need to live successfully in the community. According to Howe, et.al. (1998), providing supported living means rejecting the notion of a continuum of residential services that assumes people need to be taught the skills so they can move on to the next level of independence. They assume that people need to have the supports to experience community presence and participation in homes of their own. Rather than “fitting” people in pre-existing residential facilities that offer “pre-packaged” services, supported living means developing the supports necessary to meet the consumer’s specific needs and changing the supports as the needs and preferences change.

A study of independent living with a large number (1498) of individuals with developmental disabilities over a seven-year period was conducted by Loranzo (1993). The intent of this study was to determine the effect of independent living skills training on maintaining or improving independent living skills and remaining independent. Findings indicated that individuals who received greater amounts of independent living skill services were more likely to remain independent over the seven-year time span. The most interesting finding, however, was that the experience of living in one’s own home actually contributed more to improving and maintaining skills than provided services. Loranzo contends that independent living should be viewed as something that should be provided because it is desired rather than “earned” through skill acquisition.

Howe et.al (1998) completed a well-designed study, aimed at answering crucial questions about the implementation of supportive living in the mental health system in Oregon. They compared pairs of individuals with developmental disabilities matched for age; level of disability, gender and other factors, with one in each pair receiving supported living services and the other individual receiving more traditional services. Their findings indicated that supportive living was being implemented appropriately in most cases, with consumers owning or leasing their own home, having housemates (or none) consistent with their own preferences, having personal preferences considered during the development of the support, and being the decision makers about their own daily affairs. Further, the individuals in supportive living participated in more preferred community activities, had more social relationships and interactions outside of staff, and exercised more choice. When the costs were evaluated across the two models, no significant difference was found. These investigators also presented a discussion regarding supportive living that basically supported current skill levels, and the more intensive, independence-oriented training that can

occur in more traditional settings. Offering both types of services may be best to support differing consumer goals.

Numerous studies have been aimed at evaluating the results of this shift in models of housing and residential supports. As the first individuals to move out of institutions were typically the highest functioning, these were the first to be studied. A number of investigators have found better outcomes for consumers at reduced cost (Knobbe et.al, 1995). Stancliffe & Lakin (1998) investigated a large sample in Minnesota in which 85% were at the severe or profound level of retardation. They found improved outcomes related to community access, social activities, community inclusion, and family relationships and choice for the majority of individuals at less cost than institutional care.

Further studies demonstrate increased quality of life in community placements. In a study by Stancliffe and Lakin (1998), it was determined that community residences were less costly and had more favorable staffing and uniformly better outcomes than did institutions. In a study by Jones, et.al (1995), a matched group of former institution residents now living in the community showed significantly greater improvements in adaptive behavior than did peers who remained institutionalized.

The principle guideline regarding housing and residential supports for individuals with developmental disabilities is that they have the right to live and receive needed services in a fully inclusive, community-based environment whenever possible. Traditional residential services for adults with developmental disabilities cover a variety of settings with differing levels of supervision. Institutional settings that remain in operation have shifted to models that are similar to sub-acute care for individuals with medical, physical or psychiatric problems. These facilities are no longer considered to be long-term residences as in the past, but rather, places for rehabilitation and management of serious condition/problems with the goal of return to a community setting with a management plan in place. Community-based residential settings typically house 4-8 individuals and vary in level of intensity of services. Supportive living settings are typically tailored to the needs of the individual with supervision and supports as necessary. They may be in a wide variety of places from a family home to an apartment.

In light of the above, elements of best practice in regard to housing and residential supports include the following:

B. Best Practice System Elements

- Housing must be “unbundled” from supportive services and not made contingent on the receipt of services. Nevertheless, supportive services must be available and accessible if needed. (O’Hara, Day, 2001)
- There must be an interagency approach among health, human services, and housing agencies in developing strategies to meet supportive housing needs. This will require continued efforts by LMEs to collaborate with local, state, and federal housing resources.
- Current housing policies and practices must expand to accommodate the needs of people with disabilities.

- Reimbursement mechanisms must be expanded and current home and community-based waivers must be improved and expanded to increase flexibility. Efforts must be made to pursue waivers for specific supportive housing initiatives.
- Sources of rental assistance/operational support must be expanded to supplement SSI income.
- Inclusion of consumers and families in planning and quality management of approaches to foster independent community living.
- In summary, housing must be person-centered and unbundled, dollars should follow the person, and services should be coordinated across multiple service agencies.

C. Best Practice Related to Supports for Home Living

- Residential settings should be chosen based on consumer preference and whether the supports desired, and needed by the individual can realistically be provided in that setting.
- After determining the individual's wishes and needs, natural resources and financial options, they should be matched to available housing options. The individual and family, after choosing several options, should visit the housing environment. Once the choice is made, support must be provided in the moving process.
- The individual must be allowed to choose with whom they live.
- Supports for residential services must be highly individualized even in traditional residential settings.
- The amount and level of support needed for medical issues, safety concerns and personal care should be discussed with the individual and family members.
- Supports can range from complete care, including maximum assistance with basic self-care, to minimal assistance with occasional complex problems.
- 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 difference setting.
- Community and other natural supports should be integrated in the plan to ultimately reduce reliance on the system of care and promote integration.

D. Challenges and Barriers to Best Practice

- Availability of housing as well as residential support services within a community.
- Limited adequate and affordable housing for individuals with developmental disabilities who may have limited support income. Limited income places limits on consumer choice.
- Stigma and lack of understanding regarding individuals with developmental disabilities.
- Staff retention and turnover.
- It can be a challenge to provide the most appropriate match between the individuals and the environment in traditional residential setting that may not have enough flexibility to provide a balance between supports and training aimed at independence.

- There is considerable tension and frustration between what we would like to have happen and the realities of funding, regulations, poverty and the other limits of individual choice.

IV. Employment:

A. Discussion

Employment is considered to be an important aspect of quality of life in our society and much of the world. Considerable self worth is derived from our jobs and careers, and for many of us, most of our waking hours are spent on the job.

Historically, employment opportunities for adults with developmental disabilities have been limited. Prior to the Federal and State supported employment initiatives of the 1980's, it was assumed that persons with developmental disabilities could not function in regular work settings. In the late 1970's, research began to appear that indicated individuals with developmental disabilities could be productive in non-sheltered, competitive employment (*Rusch, Connis, Sowers, 1978*) (*Wehman, Hill, Koehler, 1979*).

Considerable evidence suggests that supported employment is more productive in terms of earnings and less costly than day programs, work activity centers and sheltered workshops (*Noble & Conley, 1987*). In a more detailed analysis of cost/benefit, Hill, (*et al. 1987*), found that although costs initially were greater than benefits, benefits increased over time and costs decreased. Unlike vocational initiatives preceding supported employment, this vocational alternative has proven to be more cost effective than its predecessors (*Rusch & Hughes, 1990*).

The major difference between supported employment and traditional vocational rehabilitation are the provisions for ongoing support and the emphasis on serving those individuals with the most severe disabilities. While vocational rehabilitation (North Carolina Division of Vocational Rehabilitation Services) provides time-limited (not more than 18 months) funding for assessment and training, the long-term supports are to be provided by the local community mental health agency. Thus, it is critical for locally driven interagency agreements to be in place in order for effective supported employment implementation (*Wehman, 1988*).

B. Supported Employment: Values and Philosophy

Supported employment programs are grounded in a set of values and philosophy that demonstrates the worth of individuals with disabilities. The following paradigms are indicators of effective supported employment programs:

- Zero Rejection

Supported employment programs assume that no one is too disabled to work. It is never a question of "readiness" in terms of the skills that an individual may or may not possess. The aim is to emphasize the assets and skills of the individual and match him/her to a job that maximizes those assets and minimizes deficits. The power of supported employment resides in the opportunity it presents to those who have traditionally been left out of the mainstream job market.

- Person-Centered

Person-centered service plans are the accepted means of planning services for consumers now and supported employment providers should also adhere to the same philosophy in planning for employment and careers. Assessment of individual skills and abilities is focused on assets and abilities as opposed to deficits. Time and consideration are given to discovering individual potential and desire in developing an employment goal. Assessment methodologies are multi-faceted and should occur in community settings where the activity typically occurs. Assessment protocols should never be used to exclude individuals from supported employment but to identify support needs.

Support strategies are interventions necessary to enable individuals to succeed in employment settings and must be identified in the person centered plan. Support strategies range from on-site training with a job coach to activities that typically occur away from the job. A holistic and proactive approach in planning support is critical to successful employment outcomes.

- Job Development is Individualized

Assessment and information regarding job preferences and desires is gathered and considered before job development occurs. This should occur with specific individuals in mind and is based on their personal skills, abilities, preferences and assets. The business community should be viewed as a secondary customer and partner in the supported employment endeavor. Effective job development identifies employer needs and establishes a “fit” with the candidate, the service to be provided and the employer’s needs, and assists the employer to understand the benefits of hiring the individual and working with the service provider.

- Choice and Job Selection

Consumers of supported employment services need to match their interests and abilities to available community jobs. Work that matches interests increases motivation (*Martin & Mithaug, 1990*). Employment factors such as working conditions, work culture, required skills and expectations are critical to employment success. Consumers of services should have knowledge of these factors in exercising informed choice in selecting a job.

- Flexibility

Service providers must understand that “one size” does not fit all consumers of service. They need to provide a variety of options and be flexible in the way that services are provided. While there are minimum standards and best practice guidelines, there is no one model for implementing supported employment programs. Many strategies for providing supported employment should emerge as adaptations and accommodations are made to specific jobs, levels of continuing support vary, and individual’s specific needs are identified. Supported employment offers the challenge to find the support approaches that match individual needs, job opportunities, local conditions and available funding (*Bellemy, Rhodes, Mank, Albin, 1988*).

C. Long Term Follow-up 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. The staff assigned to provide on-going supports, or “long term follow-up” 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. Because individuals grow and change in relation to their work experiences, the rationale for providing long term 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*). Providing long term follow-up supports and services might mean job site intervention to resolve specific problems or support away from the job with issues or situations that directly impact the consumer’s ability to maintain employment. Long term follow-up services are not time-limited. Federal guidelines stipulate that a minimum of two (2) consumer contacts per month be made after intensive job coaching has ceased. Consumer and employer need should always dictate the method and schedule for ongoing support services.

V. Social, Community, and Leisure

A. Social Skills

(1) Discussion

Social skills are an essential factor for success in community integration, including work and living environments, and therefore, are related to quality of life. Social skills, by their very nature, require some involvement on the part of the individual and cannot be totally managed through the use of outside supports.

Social skills are those skills that allow individuals to relate to one another. Social competence requires a complex set of skills, including: initiating interactions with others, being aware of and responding to pertinent situational cues, recognizing feelings in oneself and others, and controlling impulses (*AAMR, 1997*).

Ralph & Usher (1995) report that non-integration of persons with disabilities may be related to lack of knowledge of existing options, lack of knowledge of specific activities, lack of skills necessary to participate, lack of friends with whom to participate, and restrictions imposed by distance, work or home commitments. They reported that community living alone did not increase interactions with non-disabled peers. Additionally, policies aimed at increased integration of consumers with developmental disabilities in the natural community may demand more skillful social behavior from these individuals (*Part & Gaylord-Ross, 1989*).

(2) Specific Challenges

- Social skills comprise very complex behaviors and underlying cognition. It may be difficult to determine the best way to improve social skills for each individual.
- Stigma, attitude and fear in the community on the part of non-disabled individuals may interfere with the use of social skills by individuals with developmental disabilities.
- Lack of opportunities to interact with non-disabled peers may limit ability to learn social skills.
- Individuals with a history of institutionalization may have had very limited opportunities to learn and practice skills.

(3) Best Practice Related to Supports for Social Skills

- Use of the person centered planning process to identify people chosen by the individual to participate in identifying hopes, dreams, and wishes that might be met through improved social skill.
- Support the individual in developing new social skills in community based and natural settings.
- Individuals must choose to work on the social skills that they see as important.
- Encourage and support the individual in using effective social skills in their natural environment and educate families and others in how to do this. Long-term support may always be needed and this is always appropriate.
- 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.
- Support the individual in identifying emotions and their “triggers”, and support them in developing healthy ways of expressing emotions. Encourage others to promote independence in social situations by encouraging the individual to handle problems. Provide positive feedback to encourage continued growth.

B. Community Use

(1) Discussion

Community use describes skills related to the appropriate use of community resources, including: traveling in the community, shopping, obtaining needed services, attending church or other religious organizations, and using any other public facilities (AAMR, 9th ed., 1997). Community use means much more than presence in the community. The ultimate goal is participation in a natural social network that characterizes the interdependence required by all human beings.

Historically, persons with developmental disabilities were perceived as needing full care and support from caretakers. Staff and/or families provided care and services accessed from the community on behalf of the individual. During the 1970's and 1980's, program quality and quality of life for persons with developmental disabilities was primarily viewed in terms of gains in adaptive behavior (Campo, et. al., 1997). In the 1990's, this focus shifted to broader concepts of quality of life such as: lifestyle satisfaction, choice and control, social relations and community involvement. Currently, services and policies in many agencies responsible for serving the people with developmental disabilities are being driven by this concept of quality of

life. Quality of life as a treatment focus encourages a lifestyle equal to other community members. Treatment outcomes can be measured with personal satisfaction, happiness and quality of life issues versus acquisition of functional skills. Campo, (et. al., 1997) studied a group of 60 adults with profound or severe Mental Retardation to measure quality of life indicators in line with this broader definition. Using measures designed for individuals with limited communication skills, they found that quality of life was enhanced by day-to-day activities that were highly individualized, incorporated universal and basic types of human experience such as grocery shopping in the community and balancing independence with interdependence. These investigators further found that having a large number of interested family members and friends greatly increased community integration. Staff support of these relationships, and community integration in general, were important factors in the level of community integration.

(2) Specific Challenges

- Many states are struggling to meet the demand for qualified personnel to support individuals with developmental disabilities in inclusive community settings. The result of this is that many people with developmental disabilities are not receiving the services and supports that they need, and many innovative programs are poorly implemented.
- Stigma remains in the community, especially for individuals with developmental disabilities with the most severe disabilities. This creates difficulty in expecting “natural support” to facilitate community use.
- A significant number of individuals with developmental disabilities also have physical disabilities that impede access to community resources.
- The complexity of skills needed to access and use many community resources means that complex and creative supports will be necessary.

(3) Best Practice Related to Supports for Community Use

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. When considering supports, they should be considered in this order:

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

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 skill does this person need to attain to participate, but rather, what supports are necessary to make full participation a reality. Best practice includes:

- 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 should always be designed so that the individual participates in an activity as an equal partner.

- Any emphasis on skill acquisition should focus on what is functional in terms of independent living. The primary goal is to establish abilities to manage the issues of daily life. Emphasis on training any skill for no specific purpose will result in minimal success.
- An individual's dreams and desires to accomplish future goals may be enhanced by the ability of acquiring specific skills.
- The time and intensity involved in supporting an individual to learn any skill must be balanced with the individual's entire lifestyle and desires. At times, supports may be the best choice.

C. Leisure:

(1) Discussion

Leisure activities are those that we choose to do when not attending to our life's responsibilities. Regardless of the activity an individual chooses to pursue, having opportunities to engage in fun activities appears to be positively related to high quality of life (Dagnan, et. al., 1998).

Historically, persons with developmental disabilities have not had significant opportunities to choose and engage in leisure activities. Although recreation has been considered important for this population for some time, it was usually provided in a prescribed and structured manner rather than through choices made by the individual. While there are many reasons why choice has not played a large role in leisure activities for individuals with developmental disabilities, an important reason may be the widely held notion that these individuals are very limited in their ability to make choices, so choices are simply not offered. With current efforts to increase self-determination among individuals with developmental disabilities, we are finding that this assumption is not accurate (Parsons, et. al., 1997). When most individuals with developmental disabilities are exposed to various experiences of leisure activities and given support as necessary to make choices, many, if not most can have some input into what they will do with their leisure time (Rogers, et. al., 1998; Dattilo & Schleien, 1994).

Historically, many activities for individuals with developmental disabilities have been in groups segregated from the general population. Activities such as "Special Olympics" are a good example. Current philosophy supports a more inclusive approach that means opening activities. This opening seems to be a slow process. It is a challenge to find creative ways to include individuals with disabilities in traditional activities (this is a problem that crosses all disabilities). Some experts in the field of developmental disabilities are now asking whether segregated activities should be allowed at all. Little research has been done to explore this issue. Neumayer, (et. al., 1994) found, through structured interviews, that 15 of 20 adults with Down's Syndrome preferred to participate in bowling with others who had Down's Syndrome. The author makes the point that allowing true choice means offering both segregated and integrated activities to individuals.

Another area at issue for individuals with developmental disabilities is leisure across the life span. Perhaps because of the existing cognitive and physical deficits that may make a person appear child-like, age related changes and changes in leisure interests have been largely ignored. It is also important to ensure access to age and peer appropriate activities (Rogers,

et. al., 1998; Dattilo & Schleien, 1994). As more adults with developmental disabilities are surviving into older adulthood and beyond, thanks in part to improvements in health care, these issues need to be addressed.

The adult with developmental disabilities, who has significant cognitive and/or physical deficits, should be supported in enjoying as full a leisure life as possible based on individual preference. These supports may range from very basic offering of choices, to training, to increased choice ability and exposure to potentially desirable activities. Supports might also involve working with individuals and agencies in the community to increase opportunities for adults with developmental disabilities and working to decrease stigma through education. In many states, there are problems in continuity of these issues as school systems may have the sole responsibility for quality of life issues up to a certain age (often around age 25), with the mental health agency or other adult-oriented social service agency taking over at this time. It is fairly obvious that exposure to life experiences and practice in choice making will be enhanced if this is encouraged throughout life. It is hoped that the current philosophy of maximizing independence will increase the opportunities for adults in the future.

(2) Specific Challenges

- Until recently, little attention has been paid to supporting individuals with developmental disabilities in making choices about their leisure time. Many adults in the current system grew up in environments where recreation activity was structured and prescribed, and therefore, they never learned how to make choices.
- Financial resources may be very limited for adults with developmental disabilities.
- Other resources such as staffing and equipment may limit choice for adults with developmental disabilities.
- Very limited past experience with leisure activities may limit choice.
- The stigma of developmental disability may present barriers to participation in community-based leisure activities (such as joining a community softball team or a bowling league).
- Cognitive deficits may interfere with choice and full, safe participation in desired leisure activities.
- Physical deficits may interfere with participation in desired activities (such as needing a wheelchair for mobility or lack of manual dexterity).
- Deficits in other areas such as impaired social skills, sensory deficits, communication deficits, etc., may interfere with both choice and participation in leisure activities.

(3) Best Practice 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. The phone book, newspaper, local cable network, Chamber of Commerce, and city government should be checked to learn of available resources.

(4) The Importance of 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.

VI. Best Practices Related to Specific Populations

A. Autism Spectrum Disorders

Autism is a developmental disorder of neurobiologic origin that includes a spectrum of disorders that vary in severity of symptoms, age of onset, and association with other disorders such as mental retardation, language delays and epilepsy. Although there are definite commonalities, especially around social deficits, there is no single behavior that is always typical of autism. However, there are a large constellation of behaviors that define autism spectrum disorders. These behaviors generally represent deficits in social interaction, verbal and nonverbal communication, and restricted patterns of interest or behaviors. (Lord & McGee, 2001)

“Basic psychological functions such as attention, mood, intellectual functioning and motor movement are affected at the same time, and to a severe degree.” (Rapoport & Ismond, 1996)

Included within the classification of Autism Spectrum Disorders are Autistic Disorder, Asperger's Disorder, Atypical Autism, Pervasive Developmental Disorder-Not Otherwise Specified, and Childhood Disintegrative Disorder.

(1) Basic Descriptions of Disorders

(a) Autism

Autistic Disorder is the best studied and has three major features. These include qualitative impairment in social interaction and communication, and restricted, repetitive and stereotypical patterns of behavior, interests and activities. Onset of autism is prior to age three.

Autism is sometimes referred to as Early Infantile Autism or Kanner's Disorder. Kanner (1973) described the syndrome as consisting of primary symptoms which include withdrawal and an anxious, obsessive desire to maintain the status quo and secondary symptoms which include unusual object relationships, an inquiring or thoughtful appearance despite lowered intelligence, auditory impairments, language disturbances, repetitive motor behavior and hyper-sensitivity to loud noises and moving objects. The symptoms appear early in life, usually in infancy, and include self-absorption, inability to bond, and repetitive play and echolalia. If challenged, children are prone to rhythmical movements such as rocking and whirling.

In most cases, there is also a diagnosis of Mental Retardation in the moderate (35 - 50) range (DSM-IV). Receptive language, or comprehension, is often less developed than expressive language, vocabulary.

Social interaction is grossly impaired because of undeveloped non-verbal behaviors such as eye contact, meaningful facial expression, body posture and other gestures. The failure to develop appropriate peer relationships, a lack of social reciprocity and a failure to share pleasure or interests with others are typical in Autism. Further social impairments include a delay in speech communication (particularly if no effort is made to compensate by an alternate method), the inability to sustain meaningful conversation is observed, or the child has a repetitive or unusual use of language. These children also lack the ability to engage in play at appropriate developmental levels.

Behavior is often repetitive and stereotyped with an intensity that is remarkable. The syndrome includes intolerance for change and often fixed, ritualistic behaviors are common. Complex and repetitive movements and mannerisms are also common.

(b) Asperger's Disorder

Asperger's Disorder has been differentiated from Autism in that speech is less commonly delayed and intellectual skills are relatively normal. Social and behavioral peculiarities make it difficult for children with the disorder to participate in activities. The onset is later and all cases were males, although some reports of females with the syndrome have surfaced (Klin & Volkmar, 1997). Parents are usually less concerned about child development as the child may have a fascination with letters, numbers, etc. Attachments to family members are made, although reactions to others may be strange or unusual. The

onset is noted to be after age three. Asperger noted restricted, intense and almost ritualistic interests that interfered with the development of other basic skills. Clumsiness was often associated with the syndrome as well. Individuals with this condition are thought to have a better prognosis than persons with Autism and can usually live and work independently.

There is considerable criticism of the definition or existence of this syndrome (Miller & Ozonoff, 1997). The DSM-IV lists criteria as impairment in social interaction as evidenced by marked impairment in the use of nonverbal cues to regulate social interaction, failure to develop normal peer relationships, and lack of sharing pleasure or social or emotional reciprocity. The second major feature is the evidence of restricted and repetitive behaviors and interests, either in intensity or focus, adherence to ritual or non-functional routines, motor mannerisms and preoccupation with parts of objects. There is significant functional impairment, no delay in language skills, cognitive development or other age appropriate behaviors.

(c) Childhood Disintegrative Disorder

This disorder is known as Heller's Syndrome. The condition appears to be relatively rare. Early development is normal, and the child is able to speak in sentences before a profound regression is noted. After onset, the condition behaviorally resembles Autism, although the prognosis is much worse (Klin & Volkmar, 1995). The child typically loses language and self-help skills. The onset is the chief diagnostic factor and is usually between ages three and four but earlier than ten years of age. Onset can be abrupt or gradual. In addition to mutism, other symptoms of Autism-like stereotyped behaviors, resistance to change and unusual response to stimuli are noted. The child may also lose bowel and bladder control (Volkmar, 1997). Occasionally, there is a progressive neurological condition that results in death, but generally the regression stabilizes and some small gains may be seen with interventions. The DSM-IV criteria include normal development for at least the first two years, followed by a significant loss of previously acquired skills in at least two areas and abnormalities in social impairment, communication or behavior (APA, 1994).

(d) Other Pervasive Developmental Disorders - Not Otherwise Specified (Atypical Autism)

For diagnostic purposes, if a severe and pervasive impairment in social skills, communication skills and stereotypical behavior and interests are present but criteria are not met for one of the above conditions, this category may be utilized. It is used to describe children with some, but not all, of the features of Autism.

(e) Prevalence

"According to the National Institutes of Health, the incidence of autism now ranges from one in 500 births to one in 200, up from previous estimates of 1 in 666 (15 in 10,000). It is unknown whether this alarming increase is due to an actual increased incidence, expanded definition in DSM-IV, or more vigilant diagnosis." (Bartlett, et al, MADSEC, 2000) AI, 2000, MADSEC, pg 12)

2. Interventions

The following is a discussion of several interventions routinely used for children with autism. Research related to this discussion was adapted from Report of the MADSEC Autism Task Force, Feb. 2000, Maine Administrators of Services for Children with Disabilities MADSEC), Kennebec Center, 675 Western Av., Suite 2, Manchester, ME 04531. Research included extensive and exhaustive review of research literature including use of MEDLINE Advanced and PsychINFO.

(a) Applied Behavior Analysis (ABA)

“Applied behavior analysis is the process of systematically applying interventions based upon the principles of learning theory to improve socially significant behaviors to a meaningful degree, and to demonstrate that the interventions employed are responsible for the improvement in behavior.” (Baer, Wolf & Risley, 1968; Sulzer-Azaroff & Mayer, 1991) Methods used in ABA support individuals with autism in six ways: to increase behaviors, teach new skills, maintain behaviors, generalize or transfer behavior from one situation or response to another, restrict conditions under which interfering behaviors occur, and reduce interfering behaviors.

Lovaas Therapy is one method within the overarching practice of applied behavior analysis. The name was derived from O. Ivar Lovaas, PhD who researched methods of ABA for over 30 years. Based on his research, he concluded that intensive behavioral intervention offered great hope for improving outcomes. 47% of children in his study gained normal functioning such that they were virtually indistinguishable from their peers (Lovaas, 1987) These results were sustained in a 1993 follow up study. (McEachin & Lovaas, 1993) Lovaas Therapy is term that refers specifically to Lovaas’ work, methods and protocols.

Lovaas published his report of research conducted with 38 autistic children using methods of ABA 40 hours a week. The findings were significant for positive outcomes including: 47% passed “normal” first grade and scored average or above on IQ, 8 of the remaining children in treatment were successful in a language disordered classroom and scored a n average IQ of 70, those in treatment group made significant gains in IQ. The mean post-treatment IQ was 83.3 for the treatment group, while only 53.3 for the control groups. Sheinkopf and Siegel (1998) reported recently that interventions based on discrete trial training resulted in significant gains in IQ as well as reduction in symptoms of autism.

Other methods in ABA include positive behavioral support, functional assessment, and functional communication training. Positive behavioral support is the process of assisting individuals to acquire adaptive, socially meaningful behaviors, and to overcome patterns of destructive, maladaptive and stigmatizing behaviors. (Koegel, Koegel & Dunlap, 1996) A primary goal is to teach functional skills as a replacement for problem behavior.

Functional assessment is the process of gathering information that can be used to maximize the effectiveness and efficiency of behavioral support interventions. (O’Neill, et al, 1997) There are five primary outcomes of an assessment: 1) clear description of problem behaviors, 2) identification of the events, times and situations that predict problem

behavior, 3) identification of consequences that maintain behavior, development of summary statements specifying the motivating function of behavior, and collection of direct observation data that support the summary hypotheses.

Functional communication training teaches an individual to use appropriate communication to get something they want, instead of engaging in problem behavior (Hagopian, I., et al, 1998)

“There is a wealth of validated and peer-reviewed studies supporting the efficacy of ABA methods to improve and sustain socially significant behaviors in every domain, in individuals with autism. Importantly, results reported include “meaningful” outcomes such as increased social skills, communication skills academic performance, and overall cognitive functioning. These reflect clinically significant quality of life improvements. While studies varied as to the magnitude of gains, all have demonstrated long term retention of gains made. Over 30 years of rigorous research and peer review of applied behavior analysis’ effectiveness for individuals with autism demonstrate ABA has been objectively substantiated as effective based upon the scope and quality of science.” (Bartlett, et al, MADSEC, 2000, pg 29)

Between 1964 and 1970, Hingtgen & Bryson (1972) reviewed over 400 research articles and concluded that behaviorally-based interventions demonstrated the most consistent results. An additional 1100 studies were reviewed by DeMeyer, Hingtgen, and Jackson (1981 & 1982)...“the overwhelming evidence strongly suggest that the treatment of choice for maximal expansion of the autistic child’s behavioral repertoire is a systematic behavioral education program, involving as many child contact hours as possible, and using therapists (including parents) who have been trained in the behavioral techniques” (p. 435)

Baglio, Benavidiz, Compton, et al (1996) reviewed 251 studies from 1980-1995. The conclusion was that interventions based on ABA have consistently resulted in positive behavioral outcomes.

(b) TEACCH

TEACCH (Treatment and Education of Autistic and Communication Handicapped Children) is a statewide program in NC.

“According to Trehin, “TEACCH is not a single approach and even less a method. It is a state program that tries to respond to the needs of autistic people using the best available approaches and methods.” (Trehin, 1998). It is a program of services which makes use of several techniques, of several methods, in various combinations, depending upon the individual person’s unique needs and emerging capabilities.”

TEACCH was founded by Eric Schopler. The emphasis is on structured teaching which has five major components: 1)organizing and simplifying the environment, 2)developing meaningful schedules (predictability), 3)developing individual work systems, 4)utilization of visual cues in the environment, and 5) establishing positive and productive routines.

(Mesibov, et.al, 1997) The approach focuses on developing a program around a person with autism's skills, interests and needs with an emphasis on structured teaching. Other components used in the TEACCH approach include use of visual cues for instruction and prediction, (Trehin, 1998) detailed notes and data on students by psycho educational therapist and teachers (Lord and Schopler, 1994) to document outcome data of students. Components of behavioral approaches in teaching self-care skills and managing behaviors is also used. Concepts of sensory integration therapy are used to determine cause of aberrant behaviors. (Trehin, 1998).

Over 250 research studies have been conducted by or in collaboration with Division TEACCH since 1965. (Schopler , 1991) These do not include peer-reviewed studies of outcome replications by researchers not affiliated with TEACCH. "Research conducted by TEACCH and anecdotal reports suggest TEACCH shows promise (Lord, 1991); Lord & Schopler, 1989, Lord & Schopler, 1994), but is not objectively substantiated as effective by independent researchers. Independent researcher should consider further investigation using research protocols. Professionals considering TEACCH methods should portray the program as lacking independent verification of its effectiveness, and should disclose this status to key decision makers influencing the child's intervention.

(c) Auditory Integration Training

Hypersensitive hearing of person with autism has been widely recognized by many professionals (e.g. Cordon, 1975; Delacato, 1974; Grandin & Scariano, 1986; Hayes & Gordon, 1977; Rimland, 1964). Auditory Integration Training was developed by Guy Berard, otolaryngologist, based on the theory that human behavior is conditioned by the way in which one hears. (Berard, 1993) AIT addresses hearing distortions, hyperacute hearing, and sensory processing anomalies. (Stehli, 1995) It seeks to retrain the auditory system by correcting hearing distortions.

Link (1997) presented cased studies of 3 boys with autism that received sessions of AIT. The study reviewed the impact of AIT on sound hypersensitivity, cognitive and behavioral problems. No change was found in hypersensitivity to sound, and little beneficial effect was noted on behavior or cognition.

Rimland and Edelson (1995) concluded that the lack of significant data on sound hypersensitivity did not support the use of auditory integration training. Howlin (1997) questioned this conclusion, however. A follow up study was conducted by Rimland Edelson (1994) in which parents were surveyed as to results. Results indicated most parents felt the training was beneficial. (Rimland & Edelson, 1994)

"There are few validated studies regarding the use of auditory integration training....In addition, there is currently no scientific evidence to support the effectiveness of auditory integration training in reducing hypersensitivity to sound in children with autism. According to the American Academy of Pediatric Committee on Children with Disabilities, current information does not support the use of auditory integration training and, therefore, its use is not yet warranted other than in research protocols.... Preliminary research and anecdotal reports suggest AIT may show promise (Rimland & Edelson, 1994; Rimland &

Edelson, 1995; Stehli, 1991; Stehli, 1995), but is not yet objectively substantiated as effective subject to the rigors of good science.” (Bartlett, et al, MADSEC, 2000, pg 34 & 35)

(d) Facilitated Communication

Facilitated communication (FC) is based on the concept that individuals with autism have “undisclosed literacy” (Bilken, 1990). “It is a technique wherein a facilitator touches the hand, arm or shoulder of a person with communication deficits while they jointly point to symbols, letters or word...FC is not to be confused with use of appropriately applied manual guidance or other prompts to teach communication and other skills, nor should it be confused with independent use of nonspeech communication systems that may involve letterboards, keyboards, or other symbol systems.” (ABA. 1995)

Bilken who initiated FC in the US has written the majority of articles that support FC. These studies are based on qualitative methodologies with anecdotal reports of successful intervention. None are scientifically validated. “According to Eberlin, et al (1993), “To date, all published reports of facilitated communication showing unexpected literacy skills have been based on uncontrolled or poorly controlled case study accounts.”

Blind testing conditions have been used in which facilitators were not previously aware of questions pretest, testing information was unknown, or visual stimuli undisclosed (e.g. Bebko, et al, 1996; Braman, et al, 1995, Hirshorn & Gregory, 1995; Simpson & Myles, 1995; Simpson & Myles, 1994, among others.) Subjects were not able to respond correctly to most or all questions in each of these.

Moore, et al (1993) says, “The issue of determining the origin of messages in facilitated communication is an important one for several reasons. First, from an ethical standpoint, it is imperative that communications be attributed to the correct source. While this is so for the general population, it is particularly so for people with disabilities who are less able to correct errors of attribution of this sort. Second, an accurate knowledge of a disabled person’s communication skills is necessary if service providers are to make the most suitable programs available to the person. Finally, the nature of the content of some critical communications is such that serious errors of justice may be associated with incorrectly attributed communications.”

Five organizations have issued position papers on FC that are not supportive:

American Psychological Assoc.
American Academy of child and Adolescent Psychiatry
American Speech-Language-Hearing Assoc.
American Association on Mental Retardation
Assoc. for Behavior Analysis

Overall, its effectiveness is not supported by accumulated peer-reviewed, empirically based research studies. Furthermore, the research substantiates potential harm from FC. (Foxy, 1995; Margolin, 1994, Myers, 1994)

(e) Sensory Integration

Sensory Integration (SI) is based on theories developed by Dr. A. Jean Ayres in regard to sensory-motor treatment. It is based on the premise that children with autism and other developmental delays experience dysfunction in ability to integrate and organize sensory input. Techniques include vestibular stimulation and tactile stimulation. It is direct intervention intended to improve nervous system function. “ This is done by provide in the child with enhanced levels of sensory information gleaned during physical activities that are meaningful to the child, and that elicit adaptive behaviors. (Koomar & Bundy, 1991)

Researcher Ray, King and Granid (1988) found that use of vestibular stimulation (swinging) resulted in a 15% increase in vocalizations while swinging.

Anecdotal case studies by Cook (1991) on three children with autism revealed that teachers and parents noted improvements in on-task behavior and attending skills. These results however, were based on impressions rather than empirical data.

In a study by Mason and Iwata (1990) to test the effectiveness of SI on self-injurious behaviors. It was found that SI was less effective than behavioral treatment. “Smith examined several investigations evaluating SI’s effectiveness for children with developmental disabilities (Smith, 1996). Smith concludes SI did not decrease self-injury, did not reduce ritualistic behaviors and did not show increases in motor development. Like Arendt, Smith concludes “studies on sensory integration therapy are sparse, but they have consistently yielded adverse findings.” (Smith, 1996)

Current research does not support SI although anecdotal reports suggest it may show promise.

(3) Best Practice Recommendations

- Aggressive effort should be made to encourage early screening for autism; the importance of early diagnosis and treatment is well established.
- Evidence suggests early interventions that are comprehensive and continuous are best. Early intervention programs are designed to stimulate development through intensive educational efforts. Characteristics of effective early intervention programs include:
 - Curriculum focused on functional skills
 - Highly supportive teaching environments (low staff to child ratio)
 - Use of predictability and routines
 - Functional approach to problem behaviors
 - Assistance transitioning to school
 - Family involvement(Dawson & Osterling, 1997)
- Behavior support plans should be based on the results of comprehensive functional assessments and are consistent with the values, resources and skills of those involved.
- Family and educational partners must be involved and supportive of a plan.

- Treatment approaches are not exclusive—a combination of approaches and strategies can be used.
- Most appropriate treatment must be tied to individual and family needs (person centered)
- Autism Spectrum Disorder is a complex disorder which requires complex treatment—no single method will work for everyone.
- No single treatment has ever been shown to help all aspects of the disorder, because it is a syndrome.
- Applied Behavior Analysis has been substantiated as effective based on the quality of research. Auditory Integration Training, Sensory Integration, and TEACCH show promise but have not been subjected to the rigors of good science. Research has not shown that facilitated communication is effective.

B. Challenging Behaviors

(1) Discussion of Best Practice

The Human Services Research Institute (HSRI) report “Today’s Choice, Tomorrow’s Path” published on November 23, 2001 provided a critical review of behavioral support services in North Carolina. That report identified strengths, weaknesses and inconsistencies in the supports provided to persons with challenging behaviors. Based on a review of published research, the following are essential components that should be considered a part of any programs that are developed to reduce challenging behaviors. Some of these were selected from the HSRI report and others were added based on what is considered to be best practice according to leading experts in the country.

- A therapeutic environment should be created that provides not only training but an acceptable living standard
- The primary purpose of any behavioral treatment is to assist individuals in acquiring functional skills that promotes independence
- Before any intervention strategies are implemented, a complete diagnostic evaluation should be conducted to identify factors that contribute to the presence of a skill deficit or a behavior disorder
- Behavior(s) targeted for reduction and a recording system should be clearly defined
- Other disciplines, not just Psychology, should be involved in developing the behavior support plan
- Procedures for training staff to implement the behavior support plan should be described and subsequent training documented
- Internal and external monitoring procedures to ensure program integrity should be included
- An emphasis on helping the person learn appropriate alternative behaviors should be placed
- Interventions strategies should be based on the results of the functional analysis

Although not required, persons with an applied behavior analysis background would be considered the best person for designing these types of programs and must be licensed according to rules as specified in North Carolina General Statute Chapter 90, Article 18A Psychology Practice Act (See

Appendix A for a partial summary). As indicated in Section 90-270.4 Exemption to this Article, this does not prevent members of other professions (e.g., Mental Health Counselor, Psychiatrists, Teachers, Social Workers, etc.) from providing services as long as such services are consistent with their professional training and code of ethics.

A policy statement on the Right to Effective Behavioral Treatment was written and endorsed by the Association for Behavior Analysis in 1987 (See Appendix B). This policy statement continues to reflect best practice for individuals who are recipients of treatment designed to change their behavior covering six major areas: (1) a therapeutic environment, (2) services whose overriding goal is personal welfare, (3) treatment by a competent behavior analyst, (4) programs that teach functional skills, (5) behavioral assessment and ongoing evaluation, and (6) the most effective treatment procedures available.

Behavior support plans must be developed within the context of the person centered planning process and behavior support strategies must be integrated throughout the plan to address support needed in living and working environments. Challenging behaviors cannot be addressed in isolation. Often, the driving force behind challenging behaviors is the disparity between what the individual wants out of life versus what they actually get. This requires careful consideration of organized and objective information concerning potential causes for the individual's behavior. (Bradley, et al, 2001) Insuring that an individual is getting more of the life that they desire via a well developed person centered plan is the most critical element in prevention of challenging behaviors.

C. Co-Occuring Disorders

(1) Discussion:

Co-morbidity of psychiatric disorders and mental retardation and other developmental disabilities is receiving increasing attention. In the past, such co-morbidity has often been ignored or treated as maladaptive behavior (Fuller & Sabatino, 1998). Individuals with disabilities are at a much greater risk than the rest of the population for substance abuse or dependence. "A study of adult males receiving treatment for alcoholism, for instance, revealed that 40 percent had a history indicative of learning disabilities. (Rhodes and Jasinski, 1990). Another study indicated that at least one half of persons with a substance use disorder and a coexisting disability are not being identified as such by the systems providing them services (Rehabilitation Research and Training Center on Drugs and Disability , 1996)" (Moore, 1998, pg. 1) Although much more research is needed, it has become clear that psychiatric co-morbidity with developmental disabilities is a significant concern. As consumers with developmental disabilities have been moving into community settings, these problems have become more pronounced, possibly due to increasing stressors placed on these individuals. Although diagnosis in persons with cognitive and communication difficulties remains a challenge, studies are showing that nearly all mental disorders can coexist with a developmental disability (Reber, 1992). Large-scale prevalence studies remain to be done, but early work is demonstrating that at least 10% of the de-institutionalized population of individuals with mental retardation may be dually diagnosed with a psychiatric disorder (Borthwick, 1990). Mental illness in individuals with mental retardation is higher than the general population. In NC, 3% of the population has a diagnosis of mental retardation and 20% of those individuals have an additional diagnosis of mental illness.

Current literature suggests that psychiatric disorders be considered in individuals with developmental disabilities and that diagnosis should be made using current DSM-IV criteria with modifications necessary to accommodate cognitive and communication problems that may be present (Fuller & Sabatino, 1998). Individuals with mild-to-moderate mental retardation have psychiatric symptoms similar to those that do not have a diagnosis of mental retardation. Certain symptoms such as delusions, hallucinations, ideas of reference, obsessions, seem to be experienced less frequently among those with severe and profound mental retardation. This is probably due to limitations in cognitive and symbolic processes (Gabbard, 1995). However, The validity of psychiatric diagnoses for individuals with mental retardation tends to decrease as intelligence decreases (Mikkelsen & McKenna, 99). Since often symptoms of mental illness are subjective, delusions, hallucinations and thought disorders may not be ascertained if the individual is unable to communicate them. Care therefore must be taken that issues that are secondary to a diagnosis of mental retardation are not attributed to psychopathology.

Psychiatric diagnosis of individuals with mental retardation is the same for individuals with no mental retardation, in principle. However, depending on the individual's cognitive level, especially in regard to communication skills, diagnostic approaches must be modified. The poorer the communication skills the more dependence on caregivers and direct observation. (TDMHDD Guideline, p.35)

(2) Assessment

Assessment of mental illness in individuals with mental retardation must be comprehensive; a quick medication review lasting a few minutes leading to a prescription to control behavior is not appropriate. While the basic principles of a diagnostic assessment are the same, diagnostic techniques have to be adapted to the individual's developmental level, particularly in regard to communication skills. Assessment must include:

1. Interviews with the individual and family/caregivers including a comprehensive history:
 - Presenting symptoms/behaviors
 - Assessment of functioning
 - Treatment history
 - Placements and supports
 - Family/household dynamics
 - Past evaluations including any psychological evaluations, social and developmental history, family history, medical history, and physician/nurse notes.
2. Interviews with the individual. Lack of verbal language indicates the need for a longer interview process and must:
 - Allow ample time to put the individual at ease.
 - Be adapted to the individual's communication skills. Receptive language skills often exceed expressive skills and therefore care should be taken not to limit conversation.
 - Use clear and concrete language
 - Provide reassurance and support
 - Avoid leading and yes/no questions
 - Use conversation to assess mental status rather than formal examination
 - Consider nonverbal expression and activities
3. Diagnostic formulation:

- Draft
- Follows an assessment of the total information
 - Includes the life experiences, learning, understanding and communication level of the individual
4. Medical review. Individuals with mental retardation have associated physical disabilities at a higher rate than the general population, and these can impact on behavior. Pain is the most common factor in challenging behaviors. A medical review must include:
 - Developmental history
 - Medical history
 - General medical disorders and treatment
 - Routine lab work
 5. Behavioral data. Elements include:
 - Specific behavior or symptom
 - Locations and environments where the behavior/symptom occurs
 - Events or changes in life circumstances that appear to trigger the behavior/symptom
 - How other people respond to the behavior/symptom
 - How often the behavior symptom occurs and whether there has been recent changes in frequency, duration, or intensity
 6. Evaluation of stressors. Individuals with mental retardation may be more sensitive to certain stressors that trigger or exacerbate the presenting problem. In light of this, particular attention must be paid to stressors in the assessment process. "Helping the individual, family, and caregivers deal with or eliminate stressors may sometimes be the primary target of treatment and often facilitates whatever other treatment interventions that are necessary." (TDMHDD Guideline, p. 37) Stressors may include:
 - Transitions or change
 - Interpersonal loss or rejection
 - Environmental stressors including things such as overcrowding, noise, variation in daily schedule
 - Parenting and social support issues
 - Illness or disability
 - Stigmatization due to physical or intellectual issues
 - Frustration such as the inability to communicate needs/wishes, lack of choice.
 7. Screening for substance abuse. As with anyone, details about patterns of abuse and dependence are critical to treatment that is effective. The following should be considered:
 - Alcohol and Other Drug Disorders (AOD) may include behaviors that are mistaken for mental health concerns
 - AOD can obscure a disability
 - Individuals with DD often use marijuana and alcohol to mask disability.
 - Take a history of use
 - Ask concrete questions
 - An individual's understanding of "alcohol" may be different. Be specific-rather than asking if they use alcohol, ask if they drink beer, etc.
 - Explain and define specific terminology, and ask the person to repeat their understanding of the words.
 - A history should be psychosocial and encompass all domains of life, as noted above.
- (Moore, 1998, pg36-37)

(3) Psychosocial Treatment:

Treatment approaches for individuals with mental retardation and comorbid psychiatric illness are generally the same as for individuals without mental retardation. However, modifications may need to be made to accommodate the individual's developmental level, especially in regard to communication skills. The goal of all psychosocial interventions is to achieve a maximally feasible quality of life (AACAP, 1999). As noted above, addressing or eliminating stressors is often the primary target of treatment and often facilitates other interventions. The individual must be recognized as part of a system, his or her experiences, other people, family, community and the surrounding culture. For optimal care, biological, and sociological aspects of care must be acknowledged and addressed. Treatment approaches include:

- Individual and/or family education
- Applied Behavior Analysis, including positive behavioral supports and functional assessment
- Management of the environment using practical approaches such as consistent routines, likes and needs evaluation, etc.
- Supportive counseling

(McEwen, 2000)

- Individual Psychotherapy can be effective toward realization of goals such as:
 - Mitigation of stressors
 - Improved coping skills; improved communication of feelings, problems, etc.
 - Improved problem solving skills
 - Reduction/elimination of maladaptive behaviors
 - Understanding of disability and illness
 - Increased self-esteem
- Group, individual, or family psychotherapy may be appropriate for persons with mental retardation; however, the approach to therapy must be more concrete, repetitive, and/or directive, and may include visual and auditory aids. Other approaches may include role-play, and behavior modification, such as positive reinforcement. In general, the lower the cognitive and adaptive functioning of the individual, the more those modifications will be required.
- Group therapy has the potential to address a wide range of emotional, behavioral and life problems. Through group dynamics and peer interaction, learning and development of new skills can be promoted, such as decision making, problem solving, socialization, and maintaining behavioral change.
- Family therapy focuses on parents' and other family members' identification and support of the person's strengths and the provision of opportunities for success.

(TDMHDD Guidelines)

(4) Considerations in Treatment of Individuals with Cognitive Disabilities and Substance Abuse

- Individuals with cognitive disabilities may not recognize the negative consequences of substance abuse. Supporting individuals in understanding the effects of substance abuse on other aspects of their life may give strong motivation for sobriety.
- Plan small steps to meet goals.
- When counseling is provided, the room should be free of distractions in the environment such as noise and visual distracters.
- Session times should be flexible-shortened or lengthened, depending on the individual
- Disability issues should be discussed in individual sessions and not in a group setting, which may make the individual uncomfortable.
- Consideration must be given to the individual's insight and their behavior.
- Materials should be organized in advance, and goals stated clearly and often.
- Use of aids to assist with memory, such as memory books or cards.
- People with cognitive disabilities often have difficulty transferring knowledge from one setting to another. Consequences of substance abuse must be repeated frequently.
- Discussions must be concrete.
- Use of alternative media, such as videos may be helpful
- Do not assume that insight into drinking will affect other substance abuse
- Do not assume "too little"; many individuals with cognitive disabilities are just as capable of having insight..."when I drink and drug, I get in trouble".
- Reiterate role of substance abuse in crisis situations.

(Moore, 1998, pg. 46,51,55-56) Consider Minkoff literature

(5) Medication Treatment:

As previously noted psychiatric co-morbidity with developmental disabilities is a significant problem. One consequence of this is that individuals with mental illness/developmental disabilities are often given medications more indiscriminately. Communication difficulties can limit an individual's ability to report the effects and side effects of medications. Psychopharmacologic intervention should be used only after a complete assessment that addresses:

- Medical issues and health status
- Psychosocial and environmental conditions
- Current medications
- Presence of psychiatric condition
- History, previous intervention, and results
- Functional analysis of behavior
- Baseline and outcome parameters and how they will be measured.

Medication decisions should not be made in lieu of other treatments or supports that are needed. A plan for medication treatment must include consideration of the following:

- determination and assessment of the outcomes to be expected from each medication used
- lower doses should be used initially and increased more slowly than in individuals without mental retardation

- avoid frequent drug and dose changes
- identify specific index behaviors to track
- set general goals for continuing or discontinuing treatment at the outset; establish when determinations will be made
- collect baseline data before beginning medication
- track index behaviors using recognized behavioral measurement methods
- collect outcome data
- consider whether medication is compromising functional status
- maintain active treatment objectives
- determine medication blood levels if clinical situations indicate
- regular and systematic review of medication regimen should occur on an ongoing basis
- caretakers and team members should be consulted
- evaluation of side effects must be ongoing using standardized assessment instrument
- individuals on more than one medication should be monitored for drug interactions.
- education of care providers about side effects and how to detect them is essential
- medication trials should be of sufficient duration before considering a change to another medication
- polypharmacy should be avoided
- regimens should be as simple as possible
- Drugs should not be used for the convenience of staff or providers.

(McEwen, 2000)

(6)Crisis Planning

Crisis planning is inherent in any person centered planning process. Person centered planning should include both proactive and reactive crisis contingency plans. The development of crisis plans will prevent overuse and reliance on the crisis system, as well as reduce costs, time, and demands on the system.

Crisis planning must include:

- Current diagnoses (Axis I-III)
- Current medications
- Description of target behaviors that are the focus of the Crisis Plan
- Description of crisis prevention strategies
- Description of crisis interventions
- Description of crisis stabilization and support strategies
- A listing of persons, facilities, and phone numbers pertinent to the crisis plan
- Inclusion of client specific guidelines, rather than generic planning.
- Attachment of advanced directives. Advanced directives:
 - Allows a consumer's decisions that are made when competent to prevail when the consumer is incapable.
 - Can specify to withhold, as well as to provide, treatment.
 - Witnesses must not be treatment providers, owners or employees of the client's residence, or family members.

D. Medically Involved/Medically Fragile Children

(1) Discussion

With the continuing development and improvement of medical technology, the survival rate of children born extremely premature, with life threatening medical conditions, and with congenital anomalies has increased. Statistics show that approximately 10-15% of children in the United States has chronic health problems, with one million having costly disabling conditions. (ARCH of NC) The 2001 survey conducted by the Human Services Research Institute examining the needs of individuals and families waiting for developmental disability services in North Carolina found that 6% of the 1206 respondents identified their family member as being medically fragile.

For families, caring for a medically involved/medically fragile child presents a daily struggle to provide care in the home and community. The divorce rate among families with medically involved/medically fragile children is 60% higher than that of other groups. In addition, children with special needs are four times more likely to be abused (ARCH of NC). Without supports to care for their medically involved/medically fragile children, families are often left with the alternatives of 1) leaving their child in the hospital for extended periods of time, 2) hiring nurses to provide care at home, or 3) having a parent remain at home to care for the child. (Pierce et al, Prescribed Pediatric Extended Care)

As a result of grass root efforts by parents of children who are medically fragile, the North Carolina Legislature appropriated funds during the 2001 Session of the General Assembly for a demonstration child care program for this population. The outcome was the development of the NC Prescribed Pediatric Child Care Center (PPCCC), which is modeled after a program developed in Florida that is recognized as “an innovative alternative in the continuum of care” by the Congressional Task Force on Technology Dependent Children. The PPCCC is a cost-effective, developmentally appropriate, medically safe childcare setting for children who are medically fragile and require sophisticated medical treatments for extended periods of time. It encompasses a family-centered focus and addresses all of the complex health, psychosocial, and information needs of the children and their families. The PPCCC also provides training and technical assistance to other community agencies and organizations interested in providing services to children with this type of need.

The PPCCC, named Tender HealthCare, is located at the Jordan Center in Raleigh. Tender HealthCare promotes the best practices for developmental disabilities as stated in the HSRI study of 1) supporting all people in the community, and 2) embracing person and family-centered supports by responding to the unique needs and preference of each person.

Families who have medically involved/medically fragile children desire the same choices as are available to those without complex medical conditions, such a for their child to reside with their natural family and for inclusive day care, school, work, and community programs. These families need various levels of assistance so they can return to work and have some relief from the daily stress associated with caring for their children.

(2) Best Practice in Supports and Treatment

- Children that are medically involved must have a medical home to include:
 - Usual source of care for sick and preventive care
 - A personal doctor or nurse
- Referrals must be obtained when needed
- Care must be family-centered, recognizing the impact of the medical condition on the family.
- Community based service systems must be organized so that families may utilize them easily.
- Youth with special health care needs must receive the services necessary to make transitions to adult life, including adult health care, work and independence.
- Care must be taken in the person centered planning process to address transition issues including shift to adult medical care providers, changing needs, and vocational and career planning.
- Increased flexibility in respite services using state and federal dollars through a voucher model will assist in relieving the daily stress of caring for a child with high medical needs.

(Childrens Special Health Care Network Core Outcomes, 2001 SLAITS Survey)

E. Traumatic Brain Injury: Best Practice Guidelines

(1) Discussion:

A traumatic brain injury can result in physical, cognitive, behavioral, psychological and communicative changes that not only affect the individual, but the family as well. These changes result in unique needs for treatment, information, services and supports. Individuals with brain injuries have the same hopes, desires and feelings common to all people. They are entitled to the full benefits of citizenship, including all of its rights, privileges, opportunities and responsibilities.

In North Carolina, it is estimated that 36,883 people are treated and released from emergency departments each year. Estimates for those hospitalized with some mention of TBI are varied and range from 4,625 to 6,972 annually. Additional estimates are that 2,468 individuals are identified as receiving a life long disability due to a traumatic brain injury. (CDC 1995 – 2000) and (TBI NC Dept of Public Health 2003). It is difficult to determine true incidence and prevalence at this time, however we can be assured that this population is not adequately represented in current data collection systems throughout our state.

The leading causes of TBI are vehicle crashes, firearm use, and falls (Thurman 1999). Crashes involving motor vehicles, bicycles, pedestrians, and recreational vehicles are the primary causes of

TBI (Thurman 2001). Firearm use is the leading cause of death related to TBI (CDC 1999). Firearms cause about 10% of all TBIs, but they account for 44% of TBI-related deaths (CDC 1999). Nine out of 10 people with a firearm-related TBI die (CDC 1999). Nearly two-thirds of firearm-related TBIs are classified as suicidal in intent (CDC 1999).

Title XIII of the Children's Health Act of 2000 includes Traumatic Brain Injury support. It adds a national education and awareness campaign regarding traumatic brain injury to be allowed activities under certain provisions under the secretary of health and human services. These activities can be obtained through grants or contracts, to carry out related projects. The consistent theme is to reduce the incidence of such injuries.

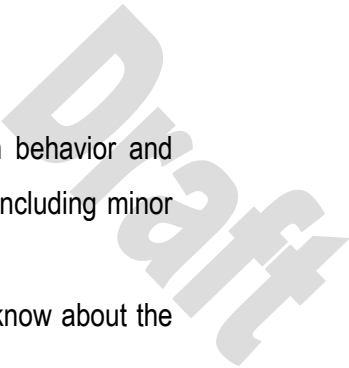
The TBI Act recommendations are:

- (1) For states to operate the state's traumatic brain injury registry
- (2) To contract with academic institutions for applied research that will support registry development
- (3) To determine appropriate methodological strategies to obtain data on the incidence and prevalence of mild traumatic brain injury
- (4) To develop a uniform reporting system for the States to report incidents of traumatic brain injury.

North Carolina received grant funding from 1997 - 2002 in the form of a demonstration grant funds to improve access to services regarding traumatic brain injury. The recommendations resulting from this initiative: TBI Project A.C.C.E.S.S. (Assuring Coordination of Care, Education and Support for Survivors); are intended for pre hospital, hospital, rehabilitation, and community agency providers.

Project A.C.C.E.S.S. recommendations include:

- Always being alert to the possibility of a brain injury even when this is not the presenting complaint.

- 
- Provide written information about symptoms of TBI and possible changes in behavior and personality to families every time an individual receives an injury to the head including minor abrasions.
 - Assure that the individual or child's primary care physician, family and school know about the injury.
 - Identify one person who can assist with the coordination of care for the individual/child throughout the acute care/rehabilitation and transition to community process.
 - Early involvement of Physical Medicine, Rehabilitation, Speech, Physical and Occupational Therapy services following trauma.
 - Set up outpatient clinics for TBI at each trauma hospital and make services available to patients from other outlying community hospitals.
 - Link families with the advocacy organizations such as the Brain Injury Association as a primary source of information, support, and referral to services.
 - Further study how best to establish a safety net of support for families who are either not ready to pursue services through the Developmental Disabilities Portal of Entry system or who do not meet developmental disabilities eligibility criteria.
 - Utilize neuropsychological evaluations within the school setting as a tool for understanding the needs of children with TBI and to assist in the development of an Individualized Education Plan.

Project A.C.C.E.S.S. is not the conclusion but merely the beginnings of potential system change that will ensure that the thousands of North Carolinians with TBI and their families receive the appropriate information, follow up care, services and supports. .

(2) Best Practice in Treatment and Supports

People with traumatic brain injuries must:

- be encouraged and supported to achieve their full potential;
- be afforded the dignity of risk; including the opportunity for supportive failure if it means giving the individual an opportunity to make his/her own decisions.
- be able to live, learn, work, play and retire in environments of their choice;

- have access to coordinated services and supports; determined by their unique strengths, needs and choices throughout their lifetime; and
be primary participants in all aspects of the planning, implementation, monitoring and evaluation of services and supports.

Service and support systems for people with traumatic brain injuries and their families must:

- emphasize education, research, information and referral and other services which prevent or lessen the impact of traumatic brain injuries;
- provide early intervention for treatment and rehabilitation;
- ensure that individualized education and related services are provided in the most inclusive and appropriate environment;
- provide safeguards to ensure freedom from harm, discrimination and stigma;
- be developed around the individual's and the family's strengths, capabilities and choices using a person-and family-centered approach;
- be provided in an environment that supports and maximizes the abilities of the individual to live and function as independently as possible;
- **include specialized services with staff who are knowledgeable about traumatic brain injury;**
- be coordinated, enabling, affordable, efficient, accountable, fully accessible and culturally sensitive; and empower survivors and their families;
- be directed by and towards the enhancement of quality of life and the achievement of independence, contribution and inclusion into the community; and
be developed as part of a system of care and linked to other services and supports in the community.

In addition:

- Cognitive Rehabilitation is an effective support for persons with Traumatic Brain Injury, providing specific recommendations for language and perception, and for the remediation of attention, memory, functional communication, and executive functioning. (Archives 2000).
- Individuals with TBI need specialized support in all aspects of service delivery. Adjustment to the new onset of a disability that changes' may be a lifelong process. By

beginning to address the effects early on, and supporting the cognitive and behavioral changes, it is determined that survivors/ consumers will better adjust.

- Community-based case management: Mild to moderate TBI accounts for many patients who are hospitalized or treated for TBI in emergency departments. Although few deaths are associated with these injuries, the economic and personal costs can be quite high. CDC has funded Baylor College of Medicine in Houston, Texas, to learn about problems resulting from mild to moderate TBI. Preliminary analysis indicates that 20% of brain-injured patients developed depression within three to six months after injury, twice the percentage of patients who sustained trauma not involving the brain. Nearly 40% of the TBI patients developed at least one of the following secondary conditions within three to six months of injury: depression, symptoms commonly resulting from concussion, or symptoms associated with stress disorders that occur with traumatic events. Of those who developed secondary conditions and were offered treatment, only 5% actually presented for treatment. (CDC 2003)

VII. Self Determination

(1) Discussion/Mounting Evidence

During the 1990s the Robert Wood Johnson Foundation awarded grants to 19 states for demonstration projects in self-determination. Common elements and strategies of these projects included individually controlled budgets, supported planning processes (person centered planning), and administration changes to make it work. In 1993 the RWJ Foundation awarded a three-year grant to Monadnock Developmental Services of Keene, NH, to assist in the implementation of self-determination principles. Results of a first year impact study in New Hampshire through the Monadnock Developmental Services offer considerable support for the premise that increased consumer involvement and control will result in more responsive and cost effective supports. (Sudders,1995) The Robert Wood Johnson Self-Determination Project in New Hampshire tested the theory that if people with disabilities and those who support them were given control of their resources and lives the quality of their life would improve and the amount of government spending would decrease. The Monadnock service organization addressed three issues:

- enabling individuals and their families to control money without dealing with case managers,
- changing the role of case management to personal agents chosen by the person,
- organizing a coherent response to managed care culture.

The following is a summary of the process and results/outcomes of the evaluation:

- New Hampshire adapted a package of instruments developed by James Conroy over a 20-year period to measure dozens of quality of life and outcomes. A new section on choice

making and personal control was added. The package was referred to as the Personal Life Quality Protocol and the personal control section was called Decision Control Inventory.

- Data was collected on participants at the beginning of the self-determination project (Time 1) and then again at 18 months (Time 2). In the report the researchers discussed what qualities of life changed among the participants during the 18-month period.
- Some of the data collection involved personal interviews and satisfaction. The average score of interviews with 27 participants at Time 1 was 67.6 (in a range of 0-100) and at Time 2 (18 months) was 74.2.
- Although all of the dimensions on the instrument reflected a higher quality of life than a Year Ago, the largest improvement in Quality of Life dimensions was in
 - happiness,
 - running my own life
 - and making my own choices.
- The average number of members in a support network more than doubled in the 18-month period. At Time 1 the average participant team was made up of 22.1% unpaid people. By Time 2 it was made up of 34.2% unpaid. Planning teams for self-determination lead a sharp increase in unpaid friends and loved ones. At Time 1, 39.7% of the average team was invited by the person, by Time 2 57.3% of the team was chosen by the person.
- There were significant behavior changes with a decrease in challenging behaviors and an increase in productive behavior. "With more opportunities to make life choices, and more hours spent in productive daytime activities, the behavior changes may be interpreted as a natural consequence of people having more responsibility for their own lives." (Independent Evaluation of the Monadnock Self-Determination Project)
- There was a lack of change in adaptive behavior but an increase in quality of life areas. Learning adaptive behavior skills such as teeth brushing, etc. was found to be less significant to increasing the quality of life. This supports the State Plan initiative to move from teaching individuals skills to focusing on person centered planning to helps people to have the life they want.
- Two methods of analysis revealed that there were cost savings. Overall, costs were reduced by between 12.4 and 15.5%. At Monadnock effort was made to design individual budgets entirely from individual needs and aspirations, and costs were shown to decrease. There was greater reliance on communities, neighbors, friends, church, etc. and the outcome of this was greater quality of life and less reliance on use of public funds.

A study has also been conducted by Wehmeyer and associates to explore the contribution of self-determination to a better quality of life and to examine the relationship between quality of life and self-determination in an empirical manner. (Wehmeyer, Schwartz, 1998) The process and findings of this study are included in the following points:

- Data was collected and analyzed on 50 individuals with mental retardation to determine the contribution of self-determination to quality of life. The core dimensions of quality of life were noted to be: emotional well-being, interpersonal relations, material well being, personal development, physical well- being, self-determination, social inclusion, and rights.
- Quality of life was measured by using the Quality of Life Questionnaire developed by Schalock and Keith, (1993). Self-determination was measured by using an adult version of the ARC's Self-Determination Scale (Wehmeyer, 1996, Wehmeyer and Kelchner, 1995). This scale was developed and normed with 500 adolescents with and without mental retardation. The amount of choice was measured by "Life Choices Survey".
- Results of this study suggest that self-determination contribute to a more positive quality of life for people with mental retardation.
- It was determined that the environments in which individuals with disabilities traditionally live inherently limit choice and thus can impact their quality of life. (Participants all lived in-group homes.) "As such, the study also supports the need to provide people with mental retardation the opportunity to live in settings which support choice and self-determination." (Wehmeyer, Schwartz, 1998)
- People who reported a higher quality of life were also identified as more self-determined.

Further impetus for continued efforts in self-determination is reflected in a study conducted through the University of Vermont by Sara Burchard, Joseph Hasazi, Lawrence Gordon, and James Yoe. (Burchard, Hasazi, Gordon, Yoe, 1991)

- This study compared residents of group homes, supervised apartments, and family homes on indices of lifestyle and adjustment living in Vermont.
- Measures of lifestyle were selected to reflect objectives of social policy, independent function, lifestyle, normalization, physical/social integration, and employment.
- Adults included in this study were similar in age, functioning level, and disability status. Individuals recruited for this study included 54 residents of group homes, 41 in supervised apartments, and 38 in family homes.
- Measures included 1) performance of adaptive behavior, 2) lifestyle measures, including the degree the residence provided opportunities for age appropriate activities, personal responsibility and autonomy of decision-making. 3) physical and social integration, 4) severity of problem behavior, 5) residential satisfaction, 6) work satisfaction, 7) social network satisfaction, and 8) personal well-being.

The results of this study support self-determination and the intent of person centered planning to help people get the lives that they desire.

- Persons in supported apartments were more independent in daily and community living skills, experienced more normalized lifestyle, and had more frequent activities in the community than persons in group homes and family homes.
- Individuals living in supported apartments engaged in two times the activities in community on a weekly basis and had more social integration. (However, it should be noted that few activities included non-handicapped peers as co-participants.)

“The results of this study point to the environmental factors of personal control and opportunity for independent behavior and for community access as exemplified by supervised apartment living in promoting lifestyle normalization, performance of adaptive behavior, community integration, and the personal satisfaction of individuals labeled with mild and moderate mental retardation. Individuals in the client-directed residences not only had the most independent and normalized lifestyles, they also expressed levels of personal satisfaction with social and residential aspects of their living and personal well being equivalent to that of individuals living in their natural families.”
(Burchard, Hasazi, Gordon, Yoe, 1991)

For many individuals, transitioning from the school setting into independent living as an adult depends upon the planning process initiated in high school. The ARC conducted a follow up study of students with mental retardation or learning disability for whom data regarding self-determination had been collected prior to high school exit. (Wehmeyer, Schwartz,1997). From 1989-1993 the US Dept. of Education, Office of Self-Determination, funded demonstration projects to promote self-determination for youth with disabilities. Self-determination has been identified as a critical outcome of transition for youth with disabilities.

- In this study data was collected regarding adult outcomes for students nearly one year after graduation or leaving school using the ARC’s Self-Determination scale. This Scale was normed with 500 students with and without disabilities in rural, urban, and suburban communities.
- “The resulting analysis determined that self-determined students were more likely to have achieved more positive adult outcomes, including being employed at a higher rate and earning more per hour than peers who were not self-determined.”
- Throughout the data there was a consistent trend for the self-determined youth to do better in general. “Members of the high self-determined group were more likely to have expressed a preference to live outside the family home, have a saving or checking account, and be employed for pay. Students who earned the most had significantly higher self-determination score and individual sub domains of self-determination contributed significantly to the students wages per hour.”

In a related study, researchers examined teacher’s knowledge and instruction of self-determination related to students with disabilities (Wehmeyer, Agran, and Hughes, 2000). One of the primary instructional activities that can promote student self-regulation of learning and, ultimately, promote self-determination is the use of student-directed learning strategies. Such strategies involve teaching students to modify and regulate their own behavior (Agran, 1997). Research in

education and vocational rehabilitation has demonstrated that student-directed learning strategies are successful as, and often more successful than, teacher-directed instructional strategies as a means to enhance learning (Wehmeyer, Agran, and Hughes, 2000). Therefore, we can conclude that individuals with disabilities will be more successful in achieving their goals if the strategies are self-directed, rather than professionally driven.

(2) Best Practice in Self-Determination

In summary, as self-determination expands in projects across the country, best practices are emerging as key components of projects that successfully support the ability of individuals to control their budgets and systems of support. Successfully operationalizing the basic principles of self-determination require that these components of best practice be pursued. These best practices include:

- Conflict of interest free. Service systems must be designed to offer support in ways that do not compromise a person's ability to freely choose among different alternatives.
- Flexible individual budgets. The overall objective is to change state service delivery systems to actively support, encourage, and enable people to directly control the services and resources they receive.
- Personally directed and controlled planning process. The planning process must reflect, as well as respect, the central role of the individual in the determination of its content and scope.
- Independent support coordination. The success of creative and individualized budgets and life plans is very much dependent on the support coordination or independent brokering.
- Autonomous fiscal intermediary services. Fiscal intermediaries should have no other duties that conflict with their roles.
- Meaningful jobs and lives. Two assumptions undergird the self-determination movement; owning their own home and producing income.
- System structure and function. Systems must be in place to address the issues that support individuals changing needs over time.

As the evidence continues to mount in support of the principles of self-determination, the need for true person centered planning, and including the individual in the community, it is imperative that NC persist in its effort to move toward a participant-driven system. "While there remains an ongoing need for additional research into self-determination and program development to achieve this outcome, professional, and parents can provide opportunities for choice and control without waiting for more data or new materials." (Wehmeyer, 1998)

The new system in NC as outlined in the State Plan focuses on moving toward best practice in the field of disabilities. As evidenced above self determination, person centered planning, and community inclusion are at the heart of best practice. We must continue to move toward the guiding principles outlined in our Mission Statement:

- Treatment, services and supports to consumers and their families shall be appropriate to needs, accessible and timely, consumer-driven, outcome oriented, culturally and age appropriate, built on consumer's strengths, cost effective, and reflective of best practices.
- Services should be provided in the most integrated community setting suitable to the needs and preferences of the individual and planned in partnership with the consumer.

VIII. Bibliography

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An outstanding reference that covers: 1) characteristics of a therapeutic environment for preventing and treating challenging behavior, 2) setting the occasion for effective implementation of behavior support plans: essential components and staff training procedures, 3) monitoring and evaluating staff proficiency in implementing behavior support plans, and 4) increasing, maintaining, and improving staff proficiency in carrying out behavior support plans.

Reid, D. H. & Parsons M. B. (2003). Positive Behavior Support Training Curriculum. Rotholz, D. A., Braswell, B. A., & Morris, L. eds. American Association on Mental Retardation.

This validated training curriculum has been designed for supervisors and direct support staff. It has all the materials that you would need to train supervisors and direct support staff on how to cope with challenging behavior before it occurs. There is a Supervisory edition (approximate costs \$395.00) and a Direct Support edition (approximate costs \$295.00). The books have been broken down into 26 modules covering all the necessary areas to assist families and staff assist people with developmental disabilities lead more independent lives. The materials can be ordered by contacting: AAMR Publications, P.O. Box 25, Annapolis Junction, MD 20701-0025 phone # 301-604-1340 email: aamr@pmds.com

Very Important Web Sites that have search engines for identification of selected research on specific challenging behaviors.

<http://www.aamr.org/>

This is the web site for the American Association on Mental Retardation. Follow the keys to the journal Mental Retardation until you find the key for journal search.

<http://www.envmed.rochester.edu/wwwrap/behavior/jaba/jabahome.htm>

This is the web site for the Journal of Applied Behavior Analysis. Follow the keys to JABA Abstracts or JABA Articles.

<http://qualitymall.org/main/>

This web site is a place where you can find lots of free information about person-centered supports for people with developmental disabilities. Each of the Mall stores has departments you can look through to learn about positive practices that help people with developmental disabilities live, work and participate in communities and improve the quality of their supports.

<http://www.nasddds.org/index.shtml>

The National Association of State Directors of Developmental Disabilities Services (NASDDDS) is a nonprofit organization, established in 1964, to improve and expand public services to people with mental retardation and other developmental disabilities. Their web site provides numerous links to federal and state resources.

<http://www.abainternational.org/>

The mission of the Association for Behavior Analysis (ABA) is to develop, enhance, and support the growth and vitality of behavior analysis through research, education and practice. The ABA web site provides information and numerous links related to applied behavior analysis including the state NCABA Chapter.

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Appendix A-Challenging Behaviors

North Carolina General Statutes Chapter 90: Medicine and Allied Occupations
Article 18A Psychology Practice Act specifies rules that apply to those individuals designing programs to address challenging behaviors.

§ 90-270.1. Title; purpose.

(a) This Article shall be known and may be cited as the "Psychology Practice Act."

(b) The practice of psychology in North Carolina is hereby declared to affect the public health, safety, and welfare, and to be subject to regulation to protect the public from the practice of psychology by unqualified persons and from unprofessional conduct by persons licensed to practice psychology. (1967, c. 910, s. 1; 1993, c. 375, s. 1.)

§ 90-270.2. Definitions.

(8) Practice of psychology. - The observation, description, evaluation, interpretation, or modification of human behavior by the application of psychological principles, methods, and procedures for the purpose of preventing or eliminating symptomatic, maladaptive, or undesired behavior or of enhancing interpersonal relationships, work and life adjustment, personal effectiveness, behavioral health, or mental health. The practice of psychology includes, but is not limited to: psychological testing and the evaluation or assessment of personal characteristics such as intelligence, personality, abilities, interests, aptitudes, and neuropsychological functioning; counseling, psychoanalysis, psychotherapy, hypnosis, biofeedback, and behavior analysis and therapy; diagnosis, including etiology and prognosis, and treatment of mental and emotional disorder or disability, alcoholism and substance abuse, of habit or conduct, as well as of the psychological and neuropsychological aspects of physical illness, accident, injury, or disability; psychoeducational evaluation, therapy, remediation, and

consultation. Psychological services may be rendered to individuals, families, groups, and the public. The practice of psychology shall be construed within the meaning of this definition without regard to whether payment is received for services rendered.

(9) Psychologist. - A person represents himself or herself to be a psychologist if that person uses any title or description of services incorporating the words "psychology", "psychological", "psychologic", or "psychologist", states that he or she possesses expert qualification in any area of psychology, or provides or offers to provide services defined as the practice of psychology in this Article. All persons licensed under this Article may present themselves as psychologists, as may those persons who are exempt by G.S. 90-270.4 and those who are qualified applicants under G.S. 90-270.5. (1967, c. 910, s. 2; 1977, c. 670, s. 1; 1979, c. 670, s. 1; 1993, c. 375, s. 1; 1993 (Reg. Sess., 1994), c. 569, s. 14; 1999-292, ss. 1, 2.)

§ 90-270.4. Exemptions to this Article.

- (f) Nothing in this Article shall be construed to prevent qualified members of other professional groups from rendering services consistent with their professional training and code of ethics, provided they do not hold themselves out to the public by any title or description stating or implying that they are psychologists or are licensed, certified, or registered to practice psychology.

Appendix B-Challenging Behaviors

The Right to Effective Behavioral Treatment

Ron Van Houten, Chair Mount Saint Vincent University,
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We propose that individuals who are recipients of treatment designed to change their behavior have the right to: (1) a therapeutic environment, (2) services whose overriding goal is personal welfare, (3) treatment by a competent behavior analyst, (4) programs that teach functional skills, (5) behavioral assessment and ongoing evaluation, and (6) the most effective treatment procedures available.

Task Force on the Right to Effective Behavioral Treatment

Executive	Council	Liaison	Commentary
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Numerous controversies involving professional groups, advocacy organizations, the courts, state legislatures, and the media have arisen in recent years over issues related to behavioral treatment. Although individual members of the Association for Behavior Analysis (ABA) have played a significant role in resolving some of these questions, the Association has never adopted a policy or issued a formal statement on the nature and use of therapeutic techniques derived from the science of behavior. Therefore, the ABA Executive Council appointed a task force in May 1986 with a charge to consider treatment-related issues, with

particular focus on clients' rights.

Chaired by Ron Van Houten, the Task Force on the Right to Effective Treatment met on several occasions, presented initial findings, and solicited feedback from ABA members in a symposium at the 1987 convention; prepared several draft documents; and submitted a final report to the Executive Council at its October 1987 meeting. The Council reviewed each draft and accepted the final report. Subsequently, the Task Force members submitted the report to the Editor of *The Behavior Analyst*, and it is contained on the following pages.

Although the Task Force report is based on input from a number of ABA members in addition to those on the task Force and the Executive Council, acceptance by the Executive Council and publication in *The Behavior Analyst* do not imply that the report reflects the view of the majority of ABA members, nor do these actions establish any of the content as Association policy. At its May 1988 meeting, the ABA Executive Council recommended that an abbreviated version of the Task Force report be prepared and sent to all voting members of ABA. Upon majority approval, that version of the document will become official Association policy.

Brian Executive Task Force on Effective Behavioral Treatment
A. Council on the Right to
Iwata Liaison to

Over the last several decades, a number of clinical procedures derived from experimental and applied behavior analysis have been developed, evaluated, and refined. These procedures have the demonstrated ability to teach new behavior and alleviate a variety of behavioral disorders. Unfortunately, many that would benefit from behavioral treatment are not receiving it. Behavior analysts have a professional obligation to make available the most effective treatment that the discipline can provide. Toward this end, the following statement of clients' rights is offered to direct both the ethical and appropriate application of behavioral treatment.

1. An Individual Has a Right to a Therapeutic Environment

A physical and social environment that is safe, humane, and responsive to individual needs is a necessary prerequisite for effective treatment. Such an environment provides not only training, but also an acceptable living standard. The dimensions of an adequate living environment are complex and varied; nevertheless, several elements appear essential. Individuals should have access to therapeutic services, leisure activities, and materials that are enjoyable as well as instructive. Thus, client preference, in addition to factors such as age-appropriateness and educative value, is relevant in the selection of activities and materials. An adequate environment also includes parents, teachers, and staff who are competent, responsive, and caring. Such qualities may be characterized in terms of frequent positive interactions that are directed toward enjoyment, learning, and independence. Finally, a therapeutic environment imposes that fewest restrictions necessary, while insuring individual safety and development. Freedom of individual movement and access to preferred activities, rather than type or location of placement, are the defining characteristics of a least restrictive environment.

2. An Individual Has a Right to Services Whose Overriding Goal is Personal Welfare

The primary purpose of behavioral treatment is to assist individuals in acquiring functional skills that promote independence. Both the immediate and long-term welfare of an individual is

taken into account through active participation by the client or an authorized proxy in making treatment-related decisions. In cases where withholding or implementing treatment involves potential risk. Peer Review Committees and Human Rights Committees play distinct roles in protecting client welfare. Peer Review Committees, comprised of experts in behavior analysis, impose professional standards in determining the clinical propriety of treatment programs. Human Rights Committees, comprised of consumers, advocates and other interested citizens, impose community standards in determining the acceptability of programs and the extent to which a program compromises an individual's basic rights to dignity, privacy, and humane care; appropriate education and training; prompt medical treatment; access to personal possessions, social interaction, and physical exercise; humane discipline; and physical examination prior to the initiation of a program that may affect or be affected by an individual's health status. Professional competence aided by peer and human rights review will insure that behavioral treatment is delivered within a context of concern for client welfare.

3. An Individual Has a Right to Treatment by a Competent Behavior Analyst

Professionals responsible for delivering, directing or evaluating the effects of behavioral treatment possess appropriate education and experience. The behavior analyst's academic training reflects thorough knowledge of behavioral principles, methods of assessment and treatment, research methodology, and professional ethics. Clinical competence also requires adequate practicum training and supervision, including experience with the relevant client population.

In cases where a problem or treatment is complex or may pose risk, individuals have a right to direct involvement by a doctoral-level behavior analyst who has the expertise to detect, analyze, and manage subtle aspects of the assessment and treatment process that often determine the success or failure of intervention. A doctoral-level behavior analyst also has the ability, as well as the responsibility, to insure that all individuals who participate in the delivery of treatment or who provide support services are trained in the methods of intervention, to assess the competence of individuals who assume subsequent responsibility for treatment, and to provide consultation and follow-up services as needed.

4. An Individual Has a Right to Programs That Teach Functional Skills

The ultimate goal of all services is to increase the ability of individuals to function effectively in both their immediate environment and the larger society. Improvement of functioning may take several forms. First, it often will require the acquisition, maintenance, or generalization of behaviors that allow the individual to gain wider access to preferred materials, activities, or social interaction. Second, it may require the acquisition of behaviors that allow the individual to terminate or reduce sources of unpleasant stimulation. Third, improved functioning may require the reduction or elimination of certain behaviors that are dangerous or that in some way serve as barriers to further independence or social acceptability. Finally, as a member of society at large, an individual has a right to services that will assist in the development of behavior beneficial to that society.

Decisions regarding the selection of service goals are not based on a priori assumptions of an individual's behavioral potential or limitations. It is conceivable that some goals might be achieved very slowly, that others may be only approximated, and that, in the process of achieving still other goals, it may be necessary to expose the individual to either immediate temporary discomfort (e.g., as in teaching physical exercise as a means of promoting health) or future risk (e.g., as in teaching an individual to cross streets or to drive an automobile). Still,

unless evidence clearly exists to the contrary, an individual is assumed capable of full participation in all aspects of community life and to have a right to such participation.

5. An Individual Has a Right to Behavioral Assessment and Ongoing Evaluation

Prior to the onset of treatment, individuals are entitled to a complete diagnostic evaluation to identify factors that contribute to the presence of a skill deficit or a behavioral disorder. A complete and functional analysis emphasizes the importance of events that are antecedent, as well as consequent, to the behavior of interest. For example, identification of preexisting physiological or environmental determinants may lead to the development of a treatment program that does not require extensive use of behavioral contingencies.

The initial behavioral analysis is performed in three stages. First, answers to the following types of questions are obtained through interview. Is there any circumstance in which the behavior never occurs? Does the behavior typically occur at certain times of the day? Could the behavior be associated with any form of discomfort or deprivation? Could events following the behavior serve as either positive reinforcement (e.g., attention) or negative reinforcement (e.g., escape from demands)? The second stage of analysis, direct observation of the individual's behavior under varied and relevant circumstances, confirms suspected relationships identified during the interview. Finally, the assessment findings are incorporated into a systematic treatment plan. Successful intervention requires ongoing evaluation in the form of objective data to determine the effects of treatment, to quickly identify unanticipated problems, and, if necessary, to modify the treatment plan. The behavior analyst maintains accountability and solicits timely input into the decision-making process by sharing these data regularly with all concerned parties.

6. An Individual Has a Right to the Most Effective Treatment Procedures Available

An individual is entitled to effective and scientifically validated treatment. In turn, behavior analysts have an obligation to use only those techniques that have been demonstrated by researchers to be effective, to acquaint consumers and the public with the advantages and disadvantages of these techniques, and to search continuously for the most optimal means of changing behavior.

Consistent with the philosophy of least restrictive yet effective treatment, exposure of an individual to restrictive procedures is unacceptable unless it can be shown that such procedures are necessary to produce safe and clinically significant behavior change. It is equally unacceptable to expose an individual to a nonrestrictive intervention (or a series of such interventions) if assessment results or available research indicate that other procedures would be more effective. Indeed, a slow-acting but nonrestrictive procedure could be considered highly restrictive if prolonged treatment increases risk, significantly inhibits or prevents participation in needed training programs, delays entry into a more optimal social or living environment, or leads to adaptation and the eventual use of a more restrictive procedure. Thus, in some cases, a client's right to effective treatment may dictate the immediate use of quicker acting but temporarily more restrictive procedures.

A procedure's overall level of restrictiveness is a combined function of its absolute level of restrictiveness, the amount of time required to produce a clinically acceptable outcome, and the consequences associated with delayed intervention. Furthermore, selection of a specific treatment technique is not based on personal conviction. Techniques are not considered as either "good" or "bad" according to whether they involve the use of antecedent rather than consequent stimuli or reinforcement rather than punishment. For example, positive

reinforcement, as well as punishment, can produce a number of indirect effects, some of which are undesirable. In summary, decisions related to treatment selection are based on information obtained during assessment about the behavior, the risk it poses, and its controlling variables; on a careful consideration of the available treatment options, including their relative effectiveness, risks, restrictiveness, and potential side effects; and on examination of the overall context in which treatment will be applied.

Conclusion

Behavior analysts have a responsibility to insure that their clients' rights are protected, that their specialized services are based on the most recent scientific and technological findings, that treatment is provided in a manner consistent with the highest standards of excellence, and that individuals who are in need of service will not be denied access to the most effective treatment available. In promulgating the rights described in this document, the field of behavior analysis acknowledges its responsibilities by reaffirming its concern for individual welfare and by prescribing the means by which behavioral treatment can be delivered in the most beneficial manner.

Appendix-Examples of Promising Practices

Examples of Promising Practices in Access include:

Pennsylvania: Single Entry Points

- Clearly identifiable place to obtain information on a wide array of community supports to individuals with mental retardation.
- Use of Web-based tool-Commonwealth of PA Application for Social Services (COMPASS)
- Provides single entry point for screening and application to include social services programs such as Food Stamps, as well as MA HCBS Waivers.
- Includes both financial and functional eligibility.

Mullen, D, Eiken, S., Steigman, D., Promising Practices in Long Term Care Systems Reform: Pennsylvania's Transformation of Supports for People with Mental Retardation, (2003, March), Medstat Research and Policy Division

www.cms.hhs.gov/promisingpractices/

Wisconsin: Resource Centers

- Resource Centers offer information to the public about a wide range of community supports available to older persons and person with disabilities.
- Single entry for HCBS
- In-depth advice in regard to long term services
- Enrolls persons in other publicly funded programs
- Determines MA eligibility
- Offers information on the full array of preventative and community social services

Alecxi, L., Olearczyk, B., Neill, C., Zeruld, S. , Wisconsin Family Care Final Evaluation Report, (2003, June), The Lewin Group

www.legis.state.wi.us/lab/reports/03-0FamilyCare.pdf

Kansas: Single Entry Points

- Services to individuals with developmental disabilities by law requires that local, nonprofit Community Developmental Disabilities Organizations (CDDOs) be single point of entry.
- Provides or arranges for service coordination
- Develops local strategic plans for improving service delivery and availability
- Manages local provider networks
- Integrates local and state funding
- Majority of governing board must be individuals with DD or members of families with individual with DD
- Entry point for HCBS waivers


Smith, G., O’Keefe, J., Carpenter, L., Doty, P., Kennedy, G., Burwell, B., Mollica, R., Williams, L., Understanding Medicaid Home and Community Based Services: A Primer, (2000, October), George Washington University Center for Health Policy Research, Washington, D. C. <http://aspe.os.dhhs.gov/daltcp/reports/primer.htm>

Examples of Promising Practices in Person Centered Planning:

- Several states have changed laws and policies to support person centered planning. These include Michigan, Hawaii, and California. <http://aspe.os.dhhs.gov/daltcp/reports/primer.htm>
- **Michigan: Person Centered Planning for People with Mental Illness, Addiction Disorders, and Developmental Disabilities**
www.mdch.state.mi.us

Examples of Promising Practices in Person Centered Service Delivery and Consumer Directed Supports:

- **Wyoming: Individual Budgets for Medicaid Waiver Services**
<http://ddd.state.wy.us>
- **New Hampshire: In-Home Support Waiver for Children with Developmental Disabilities (Consumer Directed Supports using Fiscal Intermediaries and Support Brokers)**
www.cms.hhs.gov/newfreedom/528nhhsw.pdf
- **Louisiana: New Opportunities Waiver**
www.cms.hhs.gov/newfreedom/5201anow.pdf
- **Wisconsin: Family Care Program**
Alecxi, L., Olearczyk, B., Neill, C., Zeruld, S. , Wisconsin Family Care Final Evaluation Report, (2003, June), The Lewin Group
<http://aspe.os.dhhs.gov/daltcp/reports/primer.htm>

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- **North Carolina: United Cerebral Palsy of North Carolina, Fiscal Intermediary/Employer of Record Services, Pilot Project of Community Personal Assistance Services and Supports with Maximum Consumer Control (Community PASS) Grant**
United Cerebral Palsy of NC, PO Box 27707, Raleigh, NC 27611

Examples of Promising Practices in Provider Capacity and Capabilities:

- **Massachusetts: 2001 Real Choice Systems Change Grant**
www.cms.hhs.gov/systemschange/ma-rc.pdf
- **Illinois: 2001 Real Choice Systems Change Grant**
www.cms.hhs.gov/systemschange/il-rc.pdf