Like their peers without identified disabilities, individuals with Down syndrome may display behavior that is off task, noncompliant, interferes with learning or disrupts ongoing activities. For any individual, these challenging behaviors may be occasional events or may represent consistent patterns of performance.

Just as the last 15 years have witnessed tremendous change in both the values and practice of special education, so have researchers and practitioners in the field of behavior management dramatically changed how they think about and deal with "behavior problems." There was a time when challenging behavior was treated as if it were something undesirable that had to be eliminated or reduced. This attitude focused more attention on the effectiveness of a behavior intervention (did it eliminate the challenging behavior?) than on other characteristics of the intervention (was it artificial, stigmatizing, or inappropriate in school or community settings?). There seemed to be an unstated assumption that for individuals with disabilities, any intervention was acceptable as long as it worked.

Recently school and community services for individuals with disabilities have begun to focus on lifestyle outcomes, not skill acquisition or behavior management goals in isolation. Quality programs now begin by defining a desirable lifestyle for each individual (describing presence and participation in the community, variety of activities, opportunities for choice among an array of valued activities, and so on) and then design behavioral and instructional supports necessary to ensure access to that lifestyle.

However, as school and community services have moved to include and integrate individuals with disabilities, practitioners have become more sensitive to the social
impact of behavior interventions. As society has been more strongly guided by the principle of normalization and has acknowledged the basic rights of individuals with disabilities, educators, employers and family members have been forced to question the appropriateness of some procedures that had become accepted practice. All interventions are not equal. Those that violate individual rights or that are unacceptable to normal school and community audiences now merit careful scrutiny.

Research has shown that so-called maladaptive or inappropriate behavior can serve an important function for an individual with a disability. For individuals who have limited communication skills or who lack a formal communication system, aggressive or noncompliant behavior may be the only means to communicate wants and needs or to exercise some control over the environment. Seeing students, not as "naughty," but as attempting to communicate, underscores the importance of teaching acceptable methods of communication as a way of dealing with challenging behavior.

Any effort to develop guidelines for the use of behavior management techniques is complicated by several factors. First of all, there is tremendous variability across families both in the procedures for discipline and in the standards set for acceptable behavior. What is tolerable behavior in one family may be intolerable in the next. What is an acceptable disciplinary procedure to one family may be unacceptable to another. It is difficult to offer guidelines for school and community programs when families themselves display such diversity.

A second factor that makes the discussion of behavior management difficult is the very fact that makes the discussion necessary: the horror stories of things done in the name of managing challenging behavior. There are reports of children left unattended in time-out closets for extended periods of time; of children restrained so long that they enjoy no educational programming; or individuals whose behavior is managed with chemicals in the absence of active programming; of people who are "treated" with procedures that hurt, humiliate or deny basic rights. Sometimes the "problem" seems relatively minor (e.g., failure to comply with a teacher's instruction); sometimes the challenge is clearly more significant (e.g., high rates of head banging or other self-injurious behaviors).
Despite the difficulties, it seems important to offer guidelines for the use of techniques to support individuals who exhibit challenging behavior. The guidelines are meant to help identify key features and articulate values that are consistent with quality programs for the individuals with Down syndrome. The guidelines are derived from several sources: a) the research literature on behavior management, b) model programs that implement state-of-the-art procedures and deliver effective services for people with disabilities, and c) values about the rights of individuals with disabilities and their place in society. The intent is to guide the design of services, not to condemn or condone any particular practice.

1. ANY BEHAVIOR MANAGEMENT PROGRAM SHOULD BE BASED ON A FUNCTIONAL ANALYSIS OF THE CHALLENGING BEHAVIOR.

The origin of challenging behavior is not the person with a disability but in the interaction of person and the environment. The style or manner of making requests can elicit from the person with Down syndrome tremendous cooperation or resistance. For students, behavior challenges may, in fact, reflect curriculum problems. Students who are confronted with learning tasks that are meaningless or that are the same day after day, may exhibit challenging behaviors to escape the boredom of the instructional setting. Likewise, students who repeatedly face tasks that are too demanding or lessons that fail to provide the support necessary for actual learning, are likely to develop behaviors that allow them to escape such aversive situations. Similarly, a worker who is assigned jobs that are either too difficult or insufficiently challenging may display inappropriate behavior to communicate his or her dissatisfaction.

Challenging behavior may result from poor classroom or program organization. For example, in group homes where there may be inadequate supervision, extended periods of unstructured activity, or poorly defined transitions between activities, there may be a high probability that residents will display challenging behaviors.
Behavior, whether or not it is socially acceptable, frequently serves to communicate wants, needs, or preferences. This is especially true for individuals who may not have an effective system of verbal communication. A program to eliminate "bad behavior" may in fact eliminate a person's only means of expressing a preference.

Functional analysis -- systematic observation to determine the function served by challenging behavior, the consequences that maintain it, and the circumstances that occasion it -- should be an ongoing process. Once is not enough.

The same stressors that may disrupt the behavior of people without apparent handicaps (illness, exhaustion, disruptions of routine, divorce, death of a family member, adolescence, high stimulus situations, and so on) may also lead to the display of challenging behavior by people with disabilities. Teachers, supervisors, and employers should make a reasonable effort to understand the person with a disability before identifying a "behavior problem."

2. PROGRAMS SHOULD FOCUS ON DEVELOPING COMPETENCE RATHER THAN COMPLIANCE.

The management of challenging behavior cannot occur in isolation. There is no clear line between an individual's "behavior plan" and the other aspects of his or her life. Where someone lives or works, the tasks he or she confronts on a daily basis, and opportunities for choice and control can all affect challenging behavior. All behavior plans should be part of a larger, comprehensive plan of support and development.

The goals behind any behavior programs should be to increase appropriate behavior rather than simply decrease inappropriate behavior. Programs which focus exclusively on reducing inappropriate behavior teach what not to do, not what to do.

The presence of a challenging behavior is not an excuse for the lack of positive programming. The more inappropriate behavior and individual displays, the more important it is that he or she be taught effective and appropriate ways of interacting with
Providing effective training and an organized environment are powerful strategies for managing behavior. When individuals are actively engaged in instructional activities of an appropriate level of difficulty and when the operating rules of the program are clear and consistently applied, the probability of challenging behavior is significantly reduced.

The primary strategy for dealing with challenging behavior should be positive approaches that emphasize developing adaptive and socially acceptable replacement behaviors.

3. ANY INTERVENTION PROCEDURE SHOULD BE CONSISTENT WITH THE LONG TERM GOALS OF COMMUNITY INTEGRATION.

Since the ultimate goal for students with Down syndrome is that they live, work, and play in integrated community settings, any behavioral intervention should be acceptable to and feasible in those settings. For example, if a procedure cannot be used in a regular educational setting, its use in a special education classroom is suspect.

The goal of an intervention should be to increase participation in, not remove individuals from, integrated settings and activities with peers without disabilities. Integration is as important to behavior management as it is to services in general. For example, participation in an integrated school program ensures that students will have models for appropriate behavior and that teachers have a clear reference for what amount of deviance is, in fact, age appropriate.

The standards established for appropriate behavior should reflect the standards of the natural environment. Individuals with Down syndrome should not be expected to comply or remain on task 100% of the time; most people without disabilities would be identified as having behavior problems if held to such criterion.
Programs should emphasize the use of natural consequences for behavior rather than employ elaborate or artificial reinforcers. Developing programs that rely on natural consequences increases the probability that behavior change can be maintained by the natural environment.

4. A BEHAVIOR MANAGEMENT PROGRAM SHOULD BUILD TOWARD SELF-MONITORING AND SELF-MANAGEMENT.

From the onset, the goal of a behavior intervention should be for the person to learn to manage his or her own behavior. Training an individual to monitor and evaluate his or her performance is as important as reducing the challenging behavior.

The expectations and consequences of a behavior management program should be clear and should be communicated to the person whose behavior is being addressed.

5. PARENTS OR GUARDIANS AND PERSONS WITH DOWN SYNDROME THEMSELVES SHOULD HAVE THE OPPORTUNITY TO BE INVOLVED IN ALL DECISIONS ABOUT BEHAVIOR MANAGEMENT PROGRAMS, AND IN THE DESIGN AND IMPLEMENTATION OF AGREED-UPON PROCEDURES.

Issues of motivation and behavior management should be addressed in a student's individualized education program (IEP) or an adult's individualized program plan. Parents are key members of the team which develops those plans. There should be agreement about both the goals and methods of dealing with challenging behavior.

Family involvement is critical to consistent implementation of any behavior program, Procedures to change behavior will be most effective when the same strategies can be used by individuals in the home as well as by those at school or work.

Replacing challenging behavior with socially acceptable alternatives will necessitate ongoing problem solving by teachers, parents, and others who provide services.
Procedures designed to reduce inappropriate behavior should not stigmatize, humiliate, or call unnecessary attention to an individual’s disability. The presence of a disability does not confer license for treatment that is disrespectful or dehumanizing.

In general, only procedures that would be acceptably used with individuals without disabilities should be employed to manage the behavior or individuals with disabilities. For example, if an intervention would be unacceptable for use with students without disabilities, it would be difficult to justify its use with students with disabilities.

The complexity and intrusiveness of an intervention should be balanced with the benefit that will accrue to the individual. The least intrusive intervention should be presumed to be the most appropriate one.

Procedures that are intrusive or atypical, or that appear aversive to the person, or discomforting to the teacher, employer or onlookers, should be used in limited and controlled conditions. There should be a) documentation that the program uses a functional curriculum and employs effective procedures to deliver training and support, b) a comprehensive functional analysis to ensure that the intervention has a reasonable probability of success, c) a review process to ensure informed parent consent and to verify that the nature of the challenging behavior justifies an extraordinary intervention, d) a commitment to use the procedure only on a short-term basis, e) simultaneous use of positive procedures to build appropriate behavior, and f) careful monitoring of both the person's and the trainer's behavior.

Procedures that are intrusive or atypical should never substitute for positive programming.
There are procedures for dealing with challenging behaviors that may be effective in reducing behaviors that may be effective in reducing behavior but which fail to meet other important criteria. The National Down Syndrome Congress does not support the use of procedures which

(a) involve the delivery of pain;

(b) result in tissue damage to the individual with a disability; or

(c) violate local standards of dignity and respect.

The NDSC encourages educational, employment, residential, and recreation services to adopt procedures for managing challenging behavior that

(a) acknowledge the role of environmental variables in developing and maintaining behavior;

(b) respect the dignity of the individual with a disability; and

(c) develop and support competent performance in integrated environments.

Prepared for and Approved By:
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