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Behavior

Positive Behavior Supports Creating Meaningful Life Options for People with ASD

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The Problem

When families first receive a diagnosis on the autism spectrum for their son or daughter, it is not long before they are bombarded with literature that focuses on "cure" or "recovery." For many, this goal becomes the single focus of any programming efforts. As the years progress, many families view the absence of a cure as tantamount to catastrophe. Since there is currently no known or reliably effective cure for autism, should this goal be our sole or primary focus? The desperation families feel in the absence of a cure highlights an urgent need to develop a model for successfully "living with autism" even as we pursue a model for helping individuals "recover" from autism (Carr, 2007a).

The Solution

The good news is that, through carefully designed support for positive, constructive behavior (hence, the term "positive behavior support"), it is possible to repair and enhance the quality of life for people with autism and their families (Carr et al., 2002). A support model mirrors the field of general medicine in which many chronic conditions are also not curable at present. For example, people with diabetes, arthritis, AIDS, cancer and heart disease are often not cured and, yet, with support and appropriate management, they can live fulfilling lives. So, too, can people with autism and their families.

The Vision: What Does a Meaningful Life for People with Autism Look Like?

With appropriate support, families that have a child with ASD can share a variety of activities together, just as other families do (Carr et al., 1999a). That means they can go to movies, eat at restaurants, play sports, attend religious services and even have a vacation. Children can attend a neighborhood school and participate in social and recreational activities with their peers. They can become partially or totally independent as they carry out daily life routines at home. This independence allows their parents and siblings to get on with their own lives and not simply be perpetual caregivers. Parents can be taught to replace serious problem behavior with socially appropriate behavior, and medical personnel can be trained in desensitization techniques that make physical examinations and basic diagnosis possible. These efforts help bring about a higher level of health and safety. When children become adults, they can be supported to live in a home of their own choice, with housemates of their own choice, in a neighborhood of their own choice. When they go to work, they can be helped to obtain a job that matches their interests and is meaningful to them. Not every individual with autism will experience all of the positive outcomes just described, but most will attain some and some will attain most. The result is that families become more hopeful about the future and see that the absence of a cure is not synonymous with the absence of a good life.

Barriers to Achieving the Vision

As the American poet, Delmore Schwartz, once wrote, "In dreams begin responsibilities." To realize the vision just described, we have a responsibility to address and overcome three major barriers that, collectively, prevent people with autism and their families from having a good life: skill deficits, problem behavior, and dysfunctional and unresponsive systems.

Overcoming Barriers: How Can We Do It?

There are four components that, together, constitute an effective approach for addressing critical barriers.

1. **The approach must be home and community based.** Improving the quality of life requires an approach that addresses problem behavior and skill deficits in natural situations associated with the home, school, community and workplace. Consider a simple academic skill such as learning to name colors. One can teach a child to name red versus green through prompting and differential reinforcement using colored cards. In the end, the child will learn to name two colors, which is good, but it will not impact the life of the family very much. However, one might also take the child to an intersection with a traffic light and teach that green means "Look both ways; check for traffic; and if there is none, carefully cross the road." Red means "Stay on the sidewalk and don't move." This way of teaching color names promotes independence from adults, safety, and a sense of confidence in the minds of Mom and Dad. By teaching a wide variety of skills in ways that are naturalistic and functional, we can help people with autism to overcome the barriers that set them apart from others and put them on a path to greater independence and community involvement.

   Likewise, to address problem behavior, one must focus on the natural contexts that exacerbate such behavior. These contexts involve social interactions, activities and routines, and biological factors (McAtee, Carr, & Schulte, 2004). An example of a social context would be poor communication skills that result in the child not being able to make his/her needs and frustrations known to others. These communication deficits are closely associated with tantrums, aggression, self-injury and other problem behaviors. An example of a problematic activity/routine context might involve a situation in which a preferred activity ends. Thus, a mother requests that her son stop playing with his toys (a preferred activity) and prepare for bed. The son resists and throws a tantrum. Finally, an example of a biological context would be fatigue. When a person with autism is fatigued and is pressed to complete academic work, home chores or an employment-related task, he/she is likely to respond with an outburst of problem behavior.

   Fortunately, there is a wide array of options for addressing problem behavior in naturalistic contexts (Carr et al., 1999b). The essence of all these options is that they reduce the level of frustration that people with autism experience. By addressing the issue of frustration, we undermine the necessity for problem behavior. Thus, individuals can be taught how to communicate their needs and frustrations. Academic curricula can be modified so that they represent a better fit for a particular individual's strengths. Tasks can be restructured to maximize success. Preferences can be assessed and individuals can be taught to make choices related to their preferences, thereby minimizing the frustration of seldom being able to choose what is meaningful. Visual schedules of daily events can be created so that the person with autism understands what will be happening at any given time, thereby reducing unpredictability, a factor that often generates anxiety and frustration. Poor social relationships with others can be repaired through skill training, and, most importantly, by carrying out rapport-building procedures that enhance positive interactions. When these procedures, and others, are carefully designed and systematically implemented, not only does problem behavior decrease but individuals function more effectively in a variety of contexts related to home, school, community and workplace. In other words, their quality of life improves.

2. **The approach must address the needs of the entire family and not just the person with autism.** A

sole focus on the person with autism, however skillfully done, is bound to fail if the needs of other family members are ignored. For this reason, intervention plans must be designed that are user-friendly and sensitive to the values, time constraints and personal characteristics of all members of the family system (Lucyshyn, Dunlap, & Albin, 2002). A one-size-fits-all approach is short-sighted.

Positive behavior support is defined by the partnership between the intervention agent and the family, whereby each educates the other about what is desirable, what is a priority and what is realistic. Intervention agents must not only provide parent training (i.e., techniques to enhance the development of the person with autism), but also parent support. This support takes many forms. An intervention agent must be an advocate and a resource for the family regarding local school districts, particularly when those districts are reluctant to embrace full inclusion and have few trained staff. An intervention agent must help to hire and train babysitters, respite providers, in-home education service staff and job coaches.

It is also necessary to reach out to the community, on behalf of the family, to identify barbers, dentists, doctors, pizza makers, soccer coaches, Boy Scout leaders, clergy and any others who can be persuaded and trained to help make a meaningful contribution to integrating people with autism into the community. Parenting a child with a serious disability is lonely and can provoke despair and upset siblings. Therefore, an intervention agent must facilitate parent-to-parent mentoring so that the subsequent sharing of ideas and emotional support from others who are in the same situation will motivate parents to persist in their efforts to teach their child with autism, recognize his/her strengths and remain hopeful about the future. Organizing sibling support groups is necessary for the same reasons.

Finally, parents of children with autism are no different from other parents who, occasionally, must deal with personal difficulties involving depression, anxiety, marital issues and problems with their other children. Therefore, by providing relevant psychological services to address these difficulties, an intervention agent shows sensitivity to the needs of the entire family. The approach just described helps maintain the integrity of the family, their sense of subjective well-being, their feelings of not having to go it alone, and, ultimately, their motivation and ability to carry out the tough job of helping their loved one with autism to reach his/her fullest potential.

3. The approach must focus on repairing or replacing broad dysfunctional systems that impede a better quality of life. Even the most progressive practices will fail if they are embedded in broader systems that are dysfunctional, disorganized or even antagonistic with respect to the constructive goals of positive behavior support. Therefore, it is critical to analyze and, if necessary, repair or replace any of five key elements that may be impeding progress: vision, skills, incentives, resources and an action plan (Knoster, Villa, & Thousand, 2000).

"Vision" refers to the question of whether all relevant participants (e.g., the person with ASD, parents, teachers, job coaches, direct service providers) share the same set of goals as to what constitutes a meaningful, productive life for the person with ASD and his/her family. If participants are not in agreement with one another, they are likely to be inconsistent in their approach, which will doom the effectiveness of any intervention plan. For example, if an agency is unwilling to embrace a critical goal, such as inclusion, it is time to replace that agency with another that will. More optimistically, it may be that the agency only needs to experience confidence-building measures whereby significant inclusion goals are approached gradually to maximize success, thereby providing the motivation to attempt more ambitious goals.

"Skills" refer to the ability of every participant in the system to carry out relevant support strategies. Consider a school system. Some teachers may never have worked with a child with ASD, and need to be trained and supported. Other teachers may think they know what to do but, in fact, do not. It is imperative

that they work in collaboration with the child's team to identify and adopt strategies that have proven effective with this child. If they are unwilling to adjust their teaching or to implement the recommendations of the team, then they need to be replaced with a different teacher. On day one of intervention planning, it is necessary to assess the competency level of all relevant participants and take proactive corrective measures as needed rather than wait three months to discover that the intervention plan has unraveled because of skill inadequacies or an unwillingness to implement team programming recommendations.

"Incentives" refer to the payoff that participants in the system receive for doing the right thing. Payoffs vary depending on the role of the support agent and must be identified at the beginning of any intervention effort. To continue the school system example, the payoff for a teacher may involve the realization that many procedures used to enhance the development of the child with ASD can also be used to enhance the development of every other child in the class, thereby making teaching easier and more productive. For a principal, the payoff may be that severe problem behavior can be brought under control, thereby reducing the number of unhappy parents and teachers who demand action. For the school bus driver, the payoff may be a quiet, safe trip to and from the school. By identifying relevant payoffs at the earliest stages of planning, we help ensure motivated participants who will do what is necessary to make the plan work.

"Resources" refer to factors such as time constraints, finances, transportation availability and materials that are necessary to implement support plans. Adequate financial support is always a factor but, surprisingly, it is time constraints that often prove to be the element most responsible for failed efforts. Thus, one can create an elaborate intervention plan that is so time intensive that it flies in the face of reality for a teacher who must instruct 24 other children in her class or a single mom who is working two jobs and caring for other siblings. Such a plan is virtually certain to be unworkable. Therefore, plans must be created that are user-friendly and sensitive to the realities that each support agent must confront.

Finally, **"action plan"** refers to the need to carefully delineate the roles and responsibilities of each support agent, develop a repair strategy to address the failures and weaknesses that are revealed once the plan has been implemented, and monitor the accuracy and consistency of plan implementation, taking corrective steps when deficiencies are discovered.

In sum, a systems analysis represents a strategy for ensuring that well-conceived and well-meaning plans are embedded in a context that is likely to support and enhance intervention effectiveness.

4. The approach must integrate scientific knowledge from multiple disciplines. There is no single approach to overcoming the multiple barriers that impede a good quality of life for people with ASD. They and their families need access to all reasonable options, including those based on Applied Behavior Analysis, organizational management, community/ecological psychology, cultural psychology, biomedical science and positive psychology (Carr, 2007b).

Applied Behavior Analysis (ABA) is the application of principles derived from the psychology of learning in order to teach skills and manage problem behavior. We have already discussed this approach in the section on home- and community-based intervention. Thus, teaching communication skills, restructuring tasks to promote learning, using visual schedules to reduce anxiety, encouraging choice making and building better social relationships are only a few of the many intervention options offered by ABA.

Organizational management is of great relevance to resolving the issue of deficiencies at the system level. The approach that we described for repairing or replacing dysfunctional systems is just one example of many strategies that can be derived from a knowledge of organizational management.

Community/ecological psychology, alluded to throughout our description of how to address the needs of the entire family, provides valuable information concerning prevention of family problems, building networks of social support and empowerment through advocacy efforts. These perspectives greatly increase the likelihood of intervention success in the real-world settings of home, school, community and workplace.

Cultural psychology recognizes that families are diverse with respect to ethnic, racial and religious background. Therefore, success depends upon recognizing and acting upon the fact that families differ in terms of how they define unacceptable behavior, whether specific goals are consistent with deeply held values, and how customs, family structure and child-rearing practices determine a meaningful course of action.

Biomedical science offers insight into how physical illness and chronic medical conditions, common in people with ASD, can impact social, cognitive and affective behavior as well as exacerbate problem behavior. The concept of treatment-guided research, advocated by the Autism Society of America, provides a striking opportunity for integrating the behavioral perspectives that we have been discussing with new information from biomedical science related to gastrointestinal symptoms, metabolic problems, infection, allergies and other biological factors. An emerging research base suggests that an integration of biomedical and behavioral approaches can result in benefits beyond those achieved by using either approach alone (Carr & Blakeley-Smith, 2006; Carr & Owen-DeSchryver, 2007; Carr, Smith, Giacin, Whelan, & Pancari, 2003).

Finally, the new field of **positive psychology** with its emphasis on positive emotions and positive character traits is particularly relevant to enhancing family quality of life. For example, there is a rich literature suggesting strategies for enhancing personal attributes such as gratitude, forgiveness, humor, compassion and spirituality that, when integrated with other approaches, have the potential to increase motivation and perseverance with respect to efforts to help a loved one with autism.

A Better Future

A multidimensional, comprehensive approach to ASD that emphasizes the development of positive, constructive behavior; builds family cohesiveness and mutual support; focuses on successful home and community living; and addresses systemic barriers to progress will not "cure" autism, but it will make it possible to live with autism. These goals are realistic and can be achieved now. While people with autism and their families wait for a cure, they can still have a life: a life of meaning, a life of good memories and a life of hope.

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