

Group Action Planning as a Strategy for Providing Comprehensive Family Support

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As parents of a 26-year-old man, JT, who has encountered behavioral challenges, the authors are painfully aware of the need for relevant information and especially for a comprehensive network of formal and informal supports to create inclusive, state-of-the-art lifestyle options. This chapter blends both our personal and our professional research perspectives in addressing the following high priority topics for the field of positive behavioral support:

1. The family's extensive need for comprehensive positive behavioral support
2. Criteria for measuring *lifestyle* change as contrasted to *behavioral* change
3. Group Action Planning as a strategy for providing comprehensive family support

FAMILY NEED FOR COMPREHENSIVE POSITIVE BEHAVIORAL SUPPORT

The Family Connection staff at the Beach Center on Families and Disability, where the authors conduct their research and training, completed a qualitative study that involved in-depth interviews with 17 families of individuals with problem behavior (Turnbull, Ruef, & Reeves, 1994). The study revealed two pervasive themes:

1. Many families are going to extraordinary lengths to try to create a reasonable lifestyle for their son or daughter, but most services and supports are provided in segregated settings.
2. The system has continually failed to provide even limited, much less comprehensive, support to families.

Figure 1 graphically portrays the extent of overwhelming family responsibility as a mosaic composed of the various elements (Mirenda, 1993) characterizing the lifestyles of individuals with challenging behavior. The family's extensive responsibility is depicted by the overwhelmingly prominent "tile" representing families' responsibilities and the very small tiles representing the services and supports that families receive. For example, in the Turnbull et al. (1994) qualitative inquiry, fewer than one third of the individuals with challenging behavior had even one friendship, and, of the four adults in the study, none were gainfully employed.

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Some of the comments about friendships related in the interviews included

- "Danny has no relationships outside his family."
- "Josh does not have companions or friends that he plays with."
- "Jessie has no friends at school ...she has only been there 1 1/2 years."
- "Patrick walks home from school with a paid friend." (Turnbull et al., 1994, p. 23)

In terms of employment, one family described the day program that their adult-age son attended as follows: "We have gone there three or four times and every time he is just sitting down not doing anything. He is just playing with blocks" (p. 43).

The majority of services reported were provided in segregated settings. Families described the unrelenting obligation to advocate for services and support with and from extended family, teachers, administrators, employment agencies, churches, physicians, neighbors, community citizens, and a host of others. The family responsibility of never-ending service advocacy and coordination is the "grout" in the social mosaic. It is an extremely demanding task that often limits the visions and resilience of many families. In fact, families described much more frustration in dealing with the resistance and inflexibility of the service system than in dealing with their son's or daughter's challenging behavior.

The mosaic in Figure 1 resonates deeply, given our own experience. When our son JT, along with every other student with a disability in our local community, transitioned from the high school to the *only* adult agency in town and to its segregated employment, segregated housings, segregated transportation, and segregated recreation. We have characterized that lifestyle as reflecting the "herd mentality" because adults with disabilities always move from one setting to the next in large groups, often without regard to their individual preferences.

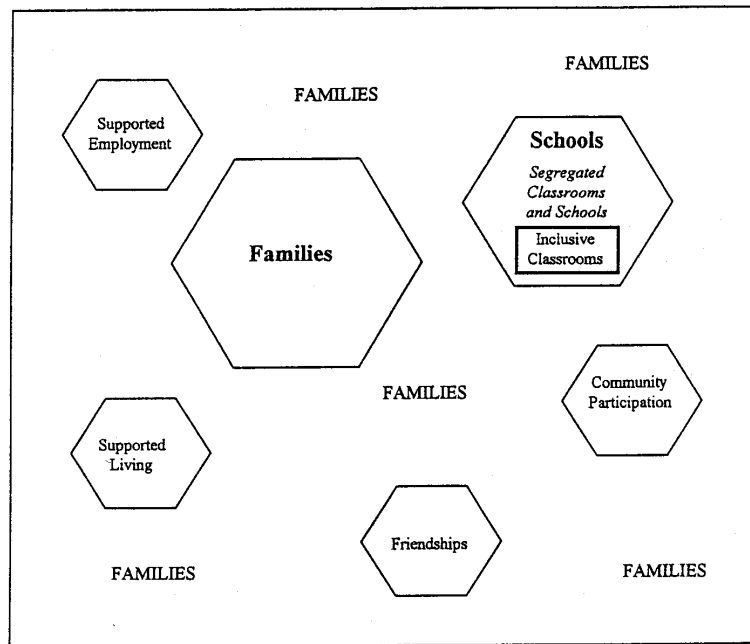
Within just a few months, JT experienced profound frustration and alienation as his life became increasingly segregated and his activities increasingly herdlike. He started hitting, choking, pulling hair, and refusing to get up in the morning. His behavior was saying loudly and clearly what he was not able to articulate: "I'm lonely. I'm afraid. I don't feel valued and respected. I feel like a second-class citizen. I'm not getting the support that I need to do the best that I can do."

After 5 months of intensive advocacy and attempts to work with and improve the adult agency, we faced the inevitable. We withdrew JT from the program just as its administrators were ready to expel him. We made this decision with two commitments in mind. First, we committed to never again subject JT to mediocrity in services. Second, we committed to developing for JT and others with disabilities a service model that is characterized by interdependence (friendships), inclusion (through supported education, supported employment, and supported living), and contribution (community participation). Underlying these two commitments was this general one: We would do all that is necessary to help JT get what he wants in life; after all, it is his life, and he has a well-developed sense of what he wants. Today, this "whatever it takes to get what he wants" attitude is called *empowerment*.

When we talked with the director of the traditional agency about our future plans for JT, his parting question was "What are you going to do when you fail?" What he was really saying was that

he ran the only program in town, that our names would be at the bottom of the waiting list, and that we would have to work our way back up to admission. At that time, our family mosaic essentially had only one tile--family--because JT had no job, no home other than with his family, no peer friends, and limited community participation.

Figure 1
Mosaic of typical supports and services for lifestyles of individuals with problem behavior



CRITERIA FOR MEASURING INCLUSIVE LIFESTYLE CHANGE

What is meant by *inclusive lifestyle change* and what criteria can behavioral consultants use to determine when their work with an individual with challenging behaviors is complete? The first part of this question can be answered by defining the two terms: *lifestyle change* and *inclusion*. Homer and colleagues (1990) describe the meaning of lifestyle change as follows:

The positive/nonaversive approach focuses on the lifestyle of the individual, in addition to the frequency, duration, and intensity of the challenging behaviors (Homer, Dunlap, & Koegel, 1988). Behavioral support should result in durable, generalized changes in the way an individual behaves, and these changes should affect the individual's access to community settings, social contacts, and to a greater array of preferred events. Among the most important issues for a technology of behavioral support is recognition that the standards for assessing "success" are changing. (p. 127)

This definition of lifestyle change properly calls for a technology (positive behavioral support) that produces desired outcomes--namely, changes in behavior that increase individuals' access to

community environments, social contacts, and a greater array of preferred events. *Inclusive lifestyle change* may be further defined by reference to interdependence (friendships and other social contacts), inclusion (supported education, supported employment, and supported living), and contribution (community participation and productivity), all as enabled by the element of *choice*, which comes alive through empowering contexts and personalized supports.

It can easily be overwhelming for families and professionals to breathe life into such a protean definition. Many professionals tend to specialize in only one life-span stage and in a relatively narrow range of issues. For example, there are behavioral consultants who typically focus on school problems, others who focus on employment, and still others who specialize in communication or social relationships. If families are fortunate enough to have a consultant at all, the consultant often concentrates on only one tile of the family mosaic and does not take into account the family's compelling need for comprehensive support across all lifestyle mosaic tiles.

Although in the field of positive behavioral support professionals are beginning to "talk the talk" of lifestyle change, there is still a way to go to "walk the walk." We are still learning how to make desirable changes for inclusive experiences, changes that are rooted in the principles of positive behavioral support, that pervade every waking and sleeping hour of the individual's life, and that cause and then reflect changes in professional systems.

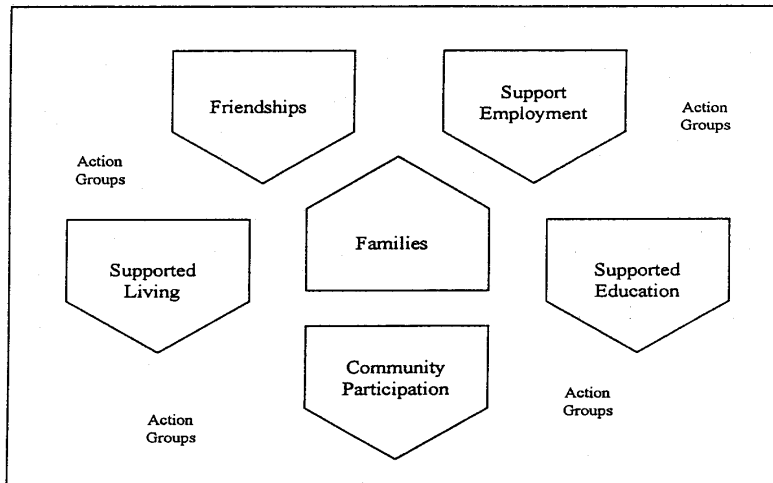
For example, current professional literature makes it clear that the "standards for assessing success" (Homer et al., 1990, p. 127) have not changed very much at all during the last decade. Studies often describe one or two intervention techniques implemented in a single environment. The question is this: Does that kind of intervention represent and ensure *inclusive lifestyle change*? In fact, long-term follow-up is often characterized by going back to the family to see how things are 3-6 months following intervention. Consider how much time would have been needed to consult with us as a family to achieve an inclusive lifestyle for JT.

It took us 6 years to put into place the lifestyle changes that balance the elements of family, friendship, community participation, supported living, and supported employment--depicted in Figure 2--despite the fact that we have six degrees between us, are immersed in the disability field, have ready access to university faculty and students, and have financial resources with which to purchase services. If it took us that long, how long will behavioral consultants need to work with typical parents, and how much support will typical families really need to make lifestyle changes--yes, profound, new paradigm-breaking lifestyle changes--that go significantly beyond mere behavioral changes?

Most professionals have not fully come to grips with the enormity of this task, the scope of time, and the financial resources it will take to provide genuine comprehensive support to achieve inclusive lifestyle change. The next section briefly highlights the mosaic of JT's life today and the process we have used to accomplish these profound lifestyle changes.

Figure 2

Mosaic of *comprehensive* supports and services for lifestyles of individuals with problem behavior



GROUP ACTION PLANNING AS A STRATEGY FOR PROVIDING COMPREHENSIVE FAMILY SUPPORT

After being asked the question, "What are you going to do when you fail?", we set out on a task where failure was absolutely unacceptable. We started out very informally, but over the years our efforts evolved into a process that we now call Group Action Planning. The two fundamental characteristics of Action Groups are that they 1) create a context for social connectedness and interdependent caring, and 2) through the social connectedness, engage in dynamic and creative problem solving and action.

The idea is to build a network with people who are passionately committed to the individual with a disability. These people include the individual with a disability, family members, friends, community citizens, and professionals. The network comes together on a regular basis to envision and create a lifestyle that is consistent with the preferences of the individual with a disability. Rather than being agency or professionally directed, Action Groups are first and foremost directed by the preferences of the individual with a disability and his or her family. Action Group members boldly view the world from the individual's perspective and ask: Why not?

Outcomes

The following have been important outcomes of Group Action Planning for JT.

Supported Employment. JT works 30 hours a week at The University of Kansas as a clerical aide. As faculty members, we were able to help him get this position; however, this is not unlike the strategy that many people without disabilities use. Many people get jobs through a network of family

and friends. JT makes more in a month than he would have made in a sheltered workshop in a year; has had only one incident of challenging behavior at work in the last 6 years; and works within a caring network of co-workers who like him, believe in him, and help him advance his skills.

Supported Living. As of this writing, JT has lived in his own home for 5 years--a home that he is helping to buy with his own salary. He shares his three-bedroom home with two university students. In exchange for rent and utilities, his roommates each provide him with about 12-15 hours a week of personal support, helping him to learn new skills, coordinate his schedule, and experience enjoyable and emotionally connected companionship.

Use of Public Transportation. Rather than riding the disability-only van, JT walks down to the corner of the block and catches the city bus, which takes him to campus. Once he gets to campus, he walks a complicated route through a couple of different buildings and down a steep hill in order to get to his job. Never in our wildest dreams did we think he would be able to do this by himself, particularly after he had experienced a 12-month period when someone always had to accompany him because of the unpredictability of his aggressive behavior.

Friendships. The most exciting aspect of JT's life is that he is surrounded by caring and enjoyable friends. Each week, he hangs out with approximately a dozen different people during different times of the week. For a young man who never had a friend his own age until he was 21 years old, he is substantially making up for lost time.

Community Participation. One of JT's first introductions to inclusion was through getting involved with a university fraternity about 5 years ago. From that beginning of having a place to hang out, with opportunities to attend parties and special activities, JT has branched out into the community in many ways.' He has many "Cheers"-like connections, places he can go where everyone knows his name, including a popular bakery, two jazz clubs, restaurants (especially ones with live music), church, a neighborhood grocery store, and a fitness center. A key aspect of JT's life is that he goes around the community as an individual rather than as a member of a herd. We continue to be awed and inspired by the number of ordinary community citizens who are invested in his success and who look out for his interests when he needs some extra support.

Group Action Planning Components

Group Action Planning components that we put into place to create the inclusive lifestyle changes described above are explained in the following sections and include: Inviting support

- Creating connections
- Envisioning great expectations
- Solving problems
- Celebrating success

Inviting Support. One of the key aspects of Action Groups is that they are composed of individuals representing each of the necessary tiles of the lifestyle mosaic. For JT, we started with his family, including both parents and his sisters, Amy and Kate; family friends; and guys JT was beginning to get to know from the fraternity. It was two of his fraternity brothers who initiated the idea of JT moving out of our home and being their roommate, and it was family friends who initiated and helped secure his job at the university. After he began to interact in these two new environments -- employment and a home of his own--his job coach, some co-workers, and his roommates became additional Action Group members. Because JT deeply enjoys music, we included a university faculty member who teaches music therapy and who, in turn, has brought dozens of musicians into JT's life.

Next, we looked for strategic community leaders who are natural "matchmakers" with inclusive community opportunities. Thus, we reached out to someone from our church, who also happens to work at the local bakery, knows almost everyone in town, and has keen communication skills, to act as a group facilitator.

The point is that Action Groups are composed of people across every single lifestyle tile because lifestyle change requires that significant supports and services be provided in each of these settings. By having significant representatives from each lifestyle tile, the supports and skill development can be coordinated, and thus JT's learning and inclusion can be far more effective. For example, everyone in his network is prompting his conversation skills using similar approaches, as contrasted to that happening in only one or two of his environments previously. Not only is the rate of his learning accelerated, but generalization is as well.

We had lived in Lawrence for 8 years before we actively invited support. It has been amazing to us what natural and potent resources we were surrounded by all of those years that were dormant because we had not invited them to be part of our lives.

Families with a member with a disability have been conditioned to assume almost sole responsibility for their family member, not to impose on others or expect their help, and generally to live on the fringe of community life. Action Groups have the major challenge and opportunity to expand support from just a sole focus on one lifestyle tile (the family) to the orchestration of all tiles (work, living, and other community environments) and from just a few professionals and parents to the rich and extensive arena of family, friends, and community citizens.

Creating Connections. At many individualized education program (IEP) and individualized transition plan (ITP) meetings, there often tends to be a routinized agenda characterized by somberness, anxiety, tension, and distance. As contrasted to the typical individualized team meetings, a teacher who attended an Action Group for a junior high student in our community commented that he could not decide if he was going to a meeting or a party. It is highly unlikely that anyone ever mistook a typical IEP or ITP meeting for a party.

Group Action Planning places strong emphasis on creating social and emotional connectedness among all group members, especially with the individual with the disability. It is typically the case that almost everyone in the group--professionals, friends, community citizens, and family--is tired and overextended from multiple responsibilities. Thus, a key in Group Action Planning is to create a context in which people can enjoy themselves, feel a sense of renewal and rejuvenation, and obtain personal gratification and validation that they are making a difference in someone's life. There have to be enough personal rewards created for each person that it is worth their valuable and limited time and energy to invest in this process, one which usually takes place outside of their typical workdays. In terms of creating social connectedness within the Action Group, key considerations include the following:

- Holding meetings in people's homes rather than in professional settings
- Telling stories about the person's past and hopes for the future rather than relying on test scores or formal reports
- Providing food and opportunities for socializing before and after meetings
- Looking for ways to enhance benefits for everyone in terms of self-esteem, gratification in making a difference, professional benefits, and responding to each member's personal needs
- Embracing crisis as a time for group solidarity in sharing both the pain of problems and the triumph of overcoming them

In addition to creating *social* connectedness, it is also critical to enhance a sense of *emotional* connectedness--not only to the individual with the disability and the family but to all group members. In terms of the individual with the disability, group members can be supported to learn how to

- Best interact with the individual so that the relationship moves beyond a superficial level to a more intimate level of emotional connectedness
- Acknowledge the individual's preferences and strengths so that those can be the basis for relationships and for transitional planning
- Encourage the individual to express positive and negative feelings and to carry on reciprocal conversations to the extent possible

For example, we found that as family members we know certain techniques that work with JT to help him feel especially connected to others. Rather than asking each new member to figure out these techniques by trial and error, we easily share examples with the Action Group so that new members can observe and quickly pick up on them. Also, many meetings start with each group member stating something positive about JT that he or she particularly appreciates. This helps everyone get to know his strengths so that they can build on those, and it is a powerful experience for JT to hear so much positive feedback. Most of the emphasis in the field of developmental disabilities has been focused on the quantity of social relationships that people experience. It is one thing for a person with a severe disability to have someone with whom to go to a movie on a Saturday night, but it is another thing to attempt to guarantee that relationship outcomes such as emotional support and companionship are derived from the interaction. Certainly, spending time together is a necessary prerequisite; however, professionals must learn to not only focus on the social connectedness of the relationship, but also learn to facilitate and document relationships that have meaningful outcomes.

We also found that JT needed to enhance the relationships he was developing--to ensure reciprocity--by expressing interest in others and responding to their instrumental and emotional needs. For example, he has expanded his conversational skills by learning information that is relevant to each of his group members, such as the names of their pets or their hobbies. It is important for him to acknowledge the happy and sad events in their lives, do thoughtful favors, and inquire about and respond to their preferences (especially when there is a conflict of interest with his own). There has not been nearly enough attention paid to relationship enhancement for people with disabilities, yet it is an essential component of an inclusive adult lifestyle.

Envisioning Great Expectations. It is essential in Group Action Planning for there to be at least some great expectations for what the future might hold. In fact, from our experience it appears that Action Groups work far more effectively when the expectations tend to be high. The challenge of reaching goals that many people foresee to be unreachable can provide motivation for group members to beat the odds.

Increasingly, there is a great deal being written about the importance of visions in future planning (see, e.g., Senge, 1990). In our own Group Action Planning, we found that great expectations grow in ever-increasing circles. It would have been absolutely impossible for us to have envisioned 7 years ago how really good life is for JT today. In fact, gradually, as one goal was reached our expectations for others became possible.

With regard to great expectations, in JT's group we found that it was essential to involve people who tended to see the cup as half-full rather than half-empty. In inviting support, it is important not to surround yourself with nay-sayers, but rather to invite people who are willing to work hard to

achieve what many people might think impossible.

Solving Problems. A key attribute of Action Groups is that they focus on creative problem solving. As contrasted to traditional team meetings where many decisions have actually been made in advance of the meeting and the discussion at meetings tends toward a review of these already established decisions, Action Groups are absolutely open in terms of assuming that any solution to a problem is possible. The group facilitator may be a professional, friend, or family member, but he or she must have excellent communication skills, as the group facilitator has a critical role in leading the group through steps of problem solving, including

1. Analyzing preferences, strengths, and needs
2. Brainstorming a wide range of options
3. Carefully evaluating each option
4. Selecting the preferred option in developing a detailed action plan
5. Implementing the plan
6. Evaluating plan outcomes

It is essential to create a problem-solving atmosphere in which everyone is open to full inquiry into all options, all group members have equal opportunities for participation, and there is a commitment to create win/win outcomes.

When there is diverse membership--especially when there are friends and community citizens participating--a whole new pool of diverse resources and options is available for solving problems, as contrasted to those available in traditional team meetings. Consideration is given to how each person can complement the efforts of others so that as many different bases as possible are covered.

In JT's Action Group, we have dealt with very large problems that require systemic change as well as smaller challenges that primarily involve learning new skills (e.g., learning to shave, learning to ride the city bus, finding new roommates). In terms of the larger systemic issues, JT went through a period after he started his job and moved into his new home where he once again started engaging in some aggressive behavior.

As we made progress in a variety of lifestyle tiles, we began to recognize that we had a proliferation of behavior management programs. JT had one behavior program that involved getting up in the morning on his own initiative, another behavior program for work motivation, and a series of fairly inconsistent attempts to encourage his appropriate behavior in afternoon and evening friendship and recreational experiences. We realized that essentially every lifestyle tile had at least one behavior program and that we were tinkering with repairing broken tiles rather than creating a mosaic.

At one Action Group meeting in the spring of 1989, one year after we had started working on the lifestyle mosaic, we squarely acknowledged as a group the grim reality that we were failing to grasp the full significance of inclusive lifestyle support. JT's roommates were instrumental in designing a comprehensive behavior support program and getting implementation under way. They made an extraordinary difference in JT's life and ours, and they supported us in grasping the magnitude of the task with which we were faced:

1. Implementing a behavior management plan that clearly specified JT's responsibilities and the rewards that he would get from the time that he got up each morning to the time he went to bed at night as he interacted in every lifestyle tile

2. Communicating among roommates, family, job coach, and friends so that *all* of the people in his life would implement the behavior management plan in a consistent manner
3. Distinguishing the unique roles of friends by seeking to incorporate only the essential aspects of behavioral programming into the relationship and avoiding the use of friends as peer tutors
4. Expanding the number of people in JT's social network and encouraging his emotional connectedness with every network member
5. Providing JT with consistent notice of schedule changes and a backup system of activities to put into place when these changes occurred
6. Training JT and group members how to handle change with confidence rather than anxiety
7. Encouraging JT to learn to express his preferences verbally and to assert himself when other people are not honoring his preferences while also encouraging members of his social network to listen, reinforce, and respond
8. Training JT to appropriately express negative emotions such as worry, frustration, anger, and fear and training his support network to listen, reinforce, and respond
9. Desensitizing JT to long, black ponytails, which he tended to pull when he experienced intense feelings of worry, frustration, anger, and fear
10. Training all group members on warning signals of JT's aggressive outbursts, how to respond to warning signals, and what to do if an outburst occurred
11. Supporting group members in envisioning great expectations and learning not to be so worried about the dangerous behavior that might happen, focusing instead on success and strengths

Attending to all of these tasks amounted to more than three full-time jobs, yet everyone in JT's Action Group had multiple other responsibilities. Unfortunately, many families feel so overwhelmed by what needs to be done that they give up on doing much of it at all.

A highly supportive aspect of JT's Action Group was that, as parents, we did not have to initiate, plan, and implement all of these interventions ourselves. With two jobs where we each typically work more than 40 hours a week and with two other children to care for besides JT, not to mention our other roles and responsibilities, it would have been extremely difficult for us to have created JT's inclusive adult lifestyle on our own. Rather, working over about a 3-year period with the help and contribution of every single Action Group member, significant progress has been made with all of the proposed tasks; however, eternal vigilance is still required for continued skill development, monitoring, and revision. What we have essentially learned is that few things last forever, but positive behavioral support is surely an ongoing process. Expanding and enhancing an inclusive adult lifestyle is a lifelong commitment, one that must continue even after the individual's parents are no longer living.

One of the best aspects of Action Groups in terms of problem solving is that the critical people are there across all of the different environments in which the person participates. Thus, there can be coordination, sharing of responsibility, and a sense of support that everyone's needs will be considered. At the end of every meeting, it is critical to write out a clear Action Plan with specific, assigned tasks to execute before the next meeting. If every member of the Action Group leaves with one task to accomplish, there can be approximately 10-14 different goals achieved without anyone feeling overwhelmed, with people helping each other, with peer support and review as a quality assurance technique, and with JT's inclusion being enhanced in all of his domains.

Celebrating Success. One of the unfortunate aspects of many traditional team meetings is that there is rarely an opportunity for celebration. The atmosphere typically tends to be somber and serious. In contrast, a key aspect of Action Groups is to take every occasion for celebration in terms

of affirming progress, allowing and encouraging gratitude, and setting aside time to "party" rather than to always problem solve.

One way to celebrate is actually to have parties, something that we have done frequently over the last 6 years. There have been opportunities for birthday parties, potluck dinners, holiday parties, and just times to have fun together. A typical approach is for JT to dictate the invitation, so that it is clear that it comes from him and that he has an opportunity to be the host. This, in turn, creates social and emotional connections by enhancing his reciprocity.

Another way to celebrate is occasionally to take time at meetings to affirm the power and contributions of the group. At one of our recent Action Group meetings, we gave everyone a candle and began the celebration by lighting only the candles of family members and showing the limited amount of light that could be generated if it was only the family light that was burning for JT. Then by going around the circle and having everyone light their candles, the vibrant blaze signified the light that could be created for JT's life by collaborating in a synergistic way. The meeting ended with JT singing "This Little Light of Mine" as a way of celebrating the progress that everyone had made by working together.

IMPLICATIONS

One of the most successful aspects of JT's Action Group has been a consistent feeling of group synergy--a powerful sense that the whole is truly rather than the sum of its parts and that the group's energy and creativity outshine what any individual could generate alone. The concept of synergy is hard to put into words. It means being with a group of people in which any individual ability to create change becomes part of a movement or wave that is unstoppable. The resulting rush of possibility and empowerment is a renewing experience, one that truly transforms great expectations from visions into lifestyle options.

Returning to an earlier question, when would a behavioral consultant know that an inclusive adult lifestyle had been accomplished for the individual with whom he or she is consulting? As Dick Schiefelbusch, our mentor at The University of Kansas, is fond of saying, "Progress is a new set of problems." For example, as soon as JT learned to ride a taxi to get to work--a task that was no small accomplishment--it occurred to us that he might be able to ride the city bus. As soon as he went through the training procedures to ride the bus to work, he then needed to learn to ride the bus from work to home--a task that involved a different set of skills in figuring out which bus to take, getting off at a different place in his neighborhood, and learning to walk a different route to his house. Similarly, as soon as JT acclimates to one roommate situation and all of the kinks are worked out, it is time to start thinking about when that roommate is going to leave, locating the next one, and beginning to reestablish these supports.

The point is that comprehensive family support in creating an inclusive lifestyle mosaic does not mean implementing procedures to handle two or even 10 behaviors within only one or two tiles. Rather, it means working cohesively and coherently, embracing complexity through the whole broad ecology of every single tile in the lifestyle mosaic over decades. Essentially, what are the new criteria for "assessing success" (Homer et al., 1990, p. 127) of lifestyle interventions? The answer to that question is that positive behavioral support for people with challenging behavior is, indeed, a lifelong intervention. We are just beginning to encounter a new era in our Action Group where increasing amounts of responsibility are being initiated by community citizens who have gotten to know JT in casual ways as he has expanded his "Cheers"-like connections. Waitpersons in restaurants provide additional support when he seems anxious, bus drivers know how to get him

home safely if he gets on the wrong bus, and people in his neighborhood watch to make sure that he gets on the bus in the morning. No one has ever asked these people to take on this role, but increasingly the community is coming forward and initiating support. Perhaps behavioral consultants will know that they have finished with creating inclusive lifestyles when the individual with challenging behavior has a reliable alliance of ordinary community citizens within each lifestyle tile. That is the next naturalistic observation we will be making as our family's mosaic continues to evolve.

Our experience with Action Groups has taught us many things, but nothing more important than what anthropologist Margaret Mead said many years ago: "Never doubt that a small group of thoughtful, committed citizens can change the world; indeed it's the only thing that ever has."

REFERENCES

Homer, R. H., Dunlap, G., & Koegel, R. L. (Eds.). (1988). *Generalization and maintenance: Life-style changes in applied settings*. Baltimore: Brookes.

Homer, R. H., Dunlap, G., Koegel, R. L., Carr, E. G., Sailor, W., Anderson, J., Albin, R. W., & O'Neill, R. E. (1990). Toward a technology of "nonaversive" behavioral support. *Journal of The Association for Persons with Severe Handicaps*, 15(3), 125-132.

Mirenda, P. (1993). AAC: Bonding the uncertain mosaic. *AAC Augmentative and Alternative Communication*, 9, 3-9.

Senge, P. M. (1990). *The fifth discipline: The art and practice of the learning organization*. New York: Doubleday.

Turnbull, A. P., Ruef, M., & Reeves, C. (1994). *Family perspectives on lifestyle issues for individuals with problem behavior* (Monograph No. P-11). Lawrence: University of Kansas, Beach Center on Families and Disability.

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