

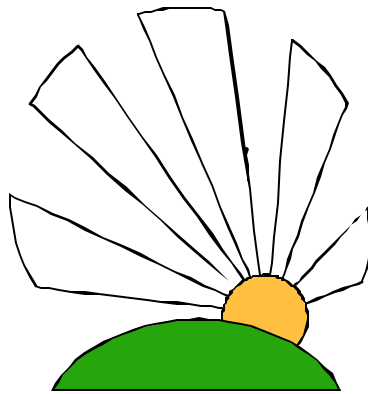
**Group Action Planning
As a Strategy for
Getting a Life**

Table of Contents

INTRODUCTION.....	1
JT—OLD HORIZONS, 1987.....	2
JT—NEW HORIZONS, 1998.....	3
Components of Group Action Planning.....	4
Inviting Support.....	5
Creating Connections.....	7
Sharing Great Expectations.....	8
Solving Problems.....	9
Celebrating Success.....	12
Implications.....	13

INTRODUCTION

During the last seven years, our family has been intensively involved in supporting our son, JT, to transition successfully from high school into an inclusive adult lifestyle. Based on our own family experience, in addition to our professional roles as special education professors with an emphasis in family support and collaboration, we will share with you our learning process in moving from old to new horizons through the strategy that has helped us—Group Action Planning.



JT—OLD HORIZONS, 1987

JT was one of the first generation students of IDEA. Throughout his school career, he most always attended special classes. He was typically physically present in typical schools but socially excluded from the life and activity of the school. The high school in our community contracted for the secondary students to attend a sheltered workshop for half of each school day. It was an automatic assumption for students to graduate into segregated employment, segregated housing, segregated transportation, and segregated recreation. We have characterized that lifestyle as the “herd mentality,” because adults with disability always move from one setting to the next in large groups often without regard to their individual preferences. Progressive transitional planning was not a hallmark of our family experience.

During JT’s last couple of years in high school, we talked frequently to his teacher, the district’s special education administrators, and the adult program administrators about supported employment models in the literature. Their response was that we were “unrealistic” and that we had not accepted the extensiveness of JT’s disability. They asked us why we thought JT should get special treatment when he was the lowest-functioning student in the class, and all of the students much more capable than he were going to the sheltered workshop. We responded by saying, “We don’t think he should have special treatment. We think *all* the students should be prepared for supported employment.”

But JT did transition into the sheltered workshop and group home, and in spite of our best efforts as members of its Board of Directors, we found it impossible to redirect the agency’s efforts toward a state-of-the-art model. Within 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 in words: “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 months of intensive advocacy in trying to work with the adult agency—the only one in town that serves adults with disabilities—we faced the inevitable. We withdrew him from the program just as the administrators were ready to expel him. We made this decision with a determination to create a service model in our community that was characterized by interdependence, empowerment, and productivity. When we talked with the traditional agency director about our future plans for JT, his parting question was, “What are you going to do when you fail?” What he was really telling us is 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. That was the period characterized by old horizons—1987.

JT—NEW HORIZONS, 1988

We will briefly highlight the major components of JT's adult life:

Job. JT works 30 hours a week at The University of Kansas as a clerical aide. Yes, we as his parents helped him get that position; but this is not unlike the strategy that many people without disabilities use. Many of us get jobs through our network of family and friends. JT makes more in a month than he would have made in the sheltered workshop in a year; has had only one incident of aggressive behavior at work in the last six years; and works within a caring network of coworkers who like him, believe in him, and help him advance his skills.

Home. This is JT's sixth year of living in his own home—a home that he is buying with his own salary. He shares his three-bedroom home with two university student roommates—Tom and Greg. In exchange for rent and utilities, his roommates each provide him about 12-15 hours a week of personal support in helping him learn new skills, coordinate his schedule, and experience enjoyable and emotionally connected companionship.

Transportation. Rather than riding the disability-only van, JT walks down to the corner of the block and catches the city bus that 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 himself, particularly during one 12-month period when someone always had to be with him because of the unpredictability of his aggressive behavior.

Friends. The most exciting aspect of JT's life is that he is surrounded with caring and enjoyable friends. Each week, he hangs out with approximately 12-15 people during different times of the week, and all of these relationships are sources of enjoyment, self-esteem, and community participation. For a young man who never had a friend his own age until he was 21 years old, he is making up for lots of lost time.

Community Participation. One of JT's first introductions to inclusion was getting involved with a university fraternity about six years ago. From that beginning of having a place to hang out and having an opportunity to attend parties and special activities, JT has branched out in lots of ways in the community. He has many "*Cheers*" connections—places he goes where everyone knows his name including the bakery, a jazz club, restaurants, (especially ones with live music), our church, 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. There are lots of people who are invested in his success and look out for his interests when he needs some extra support.

Some people have the mistaken idea that inclusion happens in a short period of time—perhaps a couple of years. We have learned that, on the contrary, creating an inclusive lifestyle

anchored within the community takes an incredibly long time. Our challenge—and indeed, the challenges of most families and professionals—is not that it takes that long to prepare the person with a severe disability; rather, it takes that long to prepare service systems and support networks that are severely restricted by bureaucracy and stereotypes.

Components of Group Action Planning

We really had no choice but to devise a radically different approach to transition planning, since being part of the only adult agency in town was not an option. We did what everyone does when they're down and out, which is to rely on the informal network of family and friends. We started out very informally, but over the years we evolved into using a process that we now call Group Action Planning. Group Action Planning occurs when the individual with a disability, family members, friends, and professionals foster a reliable alliance with each other for the purpose of creating a different vision about what life can be when one has a disability—a vision characterized by full citizenship.

The four fundamental characteristics of Action Groups are that they

- Create a context for social connectedness and interdependent caring
- Engage in dynamic and creative problem solving
- Foster the self-determination of the individual with a disability
- Adhere to the family-centered principles of support

The idea is to build a reliable alliance with people who are passionately committed to the individual with a disability. This alliance is brought 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 professional directed, Action Groups are first and foremost directed by the preferences of individuals with a disability and families. Members boldly view the world as it has never been and ask, “Why not?”

We have characterized Group Action Planning as having five major components:

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

Before you start reading these components, think of the one individual to whom you are most committed who very much wants to “get a life.” Keep that individual in your mind as you read about these components and determine what you think applies or could be adapted to apply.

Inviting Support

One of the key aspects of Action Groups is that they are comprised of individuals representing each of the valued settings of the individual and family. For JT, we started with his family, including both of us as parents, JT, and his sisters, Amy and Kate; family friends; and guys whom JT was beginning to get to know from the fraternity. It was his fraternity brothers, Cory Royer and Pat Hughes, who initiated the idea of JT moving out and being their roommate; and it was a family friend, Jean Ann Summers, who initiated and helped secure his job at Kansas University. After he began to interact in these two new settings—employment and a home of his own—his job coach, some coworkers, and his roommates became additional Action Group members. Because JT keenly enjoys music, we included Alice Ann Darrow, a KU faculty member who teaches music therapy and who, in turn, has brought dozens of musicians into JT's life. Then, we looked for strategic community leaders who are natural “matchmakers” with inclusive community opportunities. Thus, we reached out to someone from our church, Rosie Burmeister, who also happens to work at the local bakery and who simply knows almost everyone in town.

The point is that Action Groups are comprised of people across every valued setting. A key ingredient of Action Groups is *diverse* family members, neighbors, friends, and community citizens. Unlike typical individualized team meetings that primarily are dominated by professionals with usually only the mother in attendance, Action Groups recognize that intercommunity planning is far more effective than interagency planning.

By bringing together people from diverse settings associated with the home, neighborhood, job or school setting, and community, there are opportunities to explore how JT can best participate and contribute to each of those settings:



1. Home

- a. In which family and roommate relationships and activities is it important for JT to be included?
- b. Given those relationships and activities, which family members and roommates should be part of the Action Group?

2. **Neighborhood**
 - a. In which neighborhood relationships and activities is it important for JT to be included—informal gatherings, bus stop, or friendships?
 - b. Given those relationships and activities, who are the people from the neighborhood who should be invited to join the Action Group?
3. **Job**
 - a. In which job relationships and activities is it important for JT to be included?
 - b. Given those job relationships and activities, who are the people who should be invited to join the Action Group?
4. **Community**
 - a. In which community relationship and activities is it important for JT to be included—church/synagogue, restaurants, agencies, concerts, music hangouts, buses, YMCA, or bakery?
 - b. Given those relationships and activities, who are the community members who should be invited to join the Action Group?

Now, as you think about the individual to whom you are especially committed, think who the people are that you might be able to call on to begin an Action Group.

We had lived in Lawrence for eight years before we actively invited support. It has been amazing to us what natural and potent resources were surrounding us for all of those years that were all dormant, because we had not invited them to be part of our lives. It's likely the same in your community. There are far more people there than you can possibly even imagine who would be connected and empowered Action Group members. The key is for you to reach out and invite; and, if your experience is similar to ours, most of them will probably respond.

One of the very first steps is to identify someone to facilitate your group. You need someone with strong communication skills who can support others to feel connected to the group and to take specific action steps in supporting the individual to “get a life.” You might choose a facilitator who is another family member, a family friend, or a professional.

The key is to look for a person who has a demonstrative capacity to meet the Action Group goals. Once that facilitator is identified, you and that person can work together to identify potential members and issue invitations.

Creating Connections

Reflect on the IEP meetings that you have attended. What was the ambience of those meetings? How did people relate to each other? Were people confident and comfortable or did there tend 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 he couldn't decide if he was going to a meeting or a party. We don't know of anyone who ever mistook an IEP meeting for a party!

Group Action Planning places strong priorities on creating social and emotional connectedness among all group members, especially with the individual with the disability. It is a given that almost everyone—professionals, friends, community citizens, and family—are tired and overextended from multiple responsibilities. Thus, a key in Group Action Planning is to create a context where people can enjoy themselves, feel a sense of renewal and rejuvenation, and obtain personal gratification and affirmation 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 that usually is outside of their typical working days. In terms of creating the social connectedness within the Action Group, key considerations include:

- 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 visiting 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 also to all group members. In terms of the individual with the disability, group members can be supported to know 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 to communicate reciprocally 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 each new member having to figure those out by trial and error, we easily share examples in the Action Group so new members can observe and quickly pick up on them.

We also found that outside of the Action Group, JT needed to work specifically on his conversational skills and also on learning information that is relevant to each of these group members, such as the names of their pets or their hobbies. The more he can learn information that would help express interest in them, the more he can be reciprocal in that relationship. There has not been nearly enough attention paid to relationship building for people with disabilities, and it is an essential component of an inclusive lifestyle.

Sharing 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 written about the importance of visions in future planning. 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 seven years ago how really good life is for JT today. In fact, gradually, in an evolutionary fashion as one goal was reached, our expectations for others became possible to imagine.

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

One of the concrete strategies that can be used at Action Group meetings to encourage great expectations is to spend time in meetings stating something positive about the individual—a strength or a gift that can serve as the basis for enhancing expectations. Highlighting strengths and gifts helps everyone get to know the unique resources that the individual has to build upon. It is also a powerful experience for individuals with disabilities and their families to receive this

affirmation. Contrast a strengths orientation with what happens at many individualized team meetings when only test scores and deficits are emphasized. Strengths propel group members to expand their great expectations into even greater ones.

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 and the discussion tends to be to review these already established decisions, Action Groups are absolutely open in terms of assuming that anything is possible. The group facilitator has a critical role in leading the group through steps of problem solving including

- Analyzing preferences, strengths, and needs
- Brainstorming a wide range of options
- Carefully evaluating each option
- Selecting the preferred option in developing a detailed action plan
- Implementing the plan
- Evaluating the outcomes of the plan

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

Diverse membership—especially when friends and community citizens participate—creates a whole new pool of resources and options for solving problems, as contrasted to traditional meetings attended only by professionals and family members. 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 has a tendency to be aggressive toward others and damage property when his environment is not sufficiently predictable.

As we work to eliminate this challenging behavior, we began to gain insight that we had a proliferation of behavior management programs. JT had one behavioral program that involved getting up in the morning on his own initiative, another behavioral program for work motivation, and a series of fairly inconsistent behavioral attempts to encourage his appropriate behavior in afternoon and evening friendship and recreational experiences.

We distinctly remember the Action Group meeting in the spring of 1989 when we squarely acknowledged the grim reality that we were failing to grasp the full significance of the lifestyle changes that would be required to eliminate JT's challenging behavior. The crisis of an aggressive incident gave our Action Group a "wake-up call" on the real meaning of inclusive lifestyle supports. JT's roommates, Shahla and Jesus Rosales, were instrumental in designing a comprehensive positive behavioral support program and getting implementation underway. They made an extraordinary difference in JT's life and ours. They supported us to grasp the magnitude of the task we faced:

- Implementing a positive behavioral support 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.
- Communicating among roommates, family, job coach, and friends so that *all* of the people in his life would implement the positive behavioral support plan in a consistent manner.
- Distinguishing the unique roles of friends and seeking to prepare friends to offer responsive support but not to become peer tutors.
- Expanding the number of people in his social network and the emotional connections with every network member.
- Providing JT consistent notice of schedule changes and a backup system of activities to put into place when these changes occurred.
- Teaching JT to handle change with confidence rather than anxiety.
- Teaching JT to express his preferences verbally and to assert himself when other people are not honoring his preferences, and supporting the members of social network to listen, reinforce, and respond to his preferences.
- Teaching JT to express negative emotions such as worry, frustration, anger, and fear, and supporting the members of his support network to listen, reinforce, and respond.
- Preparing all Action Group members to identify warning signals of aggressive outbursts, to respond to warning signals, and to know what to do if an outburst occurred.
- Supporting all Action Group members in envisioning great expectations and learning not to be too worried about the dangerous behavior that might happen and to focus instead on successes and strengths.

We know that we will never forget the feeling we experienced at the Action Group meeting when we were debating whether we were going to move full-speed ahead into a comprehensive positive behavioral support program or whether we were going to continue to tinker with smaller details that would not be nearly as time-consuming. Another major consideration that evening

was that JT's neurologist was suggesting that he go on a second medication. JT was already taking one medication, and the neurologist suggested that the aggressive episodes would be lessened if he took an additional medication.

We recall the powerful pull of so desperately wanting a quick fix and wondering if the medication would provide the immediacy of relief. We remember the passionate commitment of Shahla and Jesus Rosales who were quite persistent in expressing their perspective that comprehensive positive behavioral support was the right approach even though it was going to be far more time-consuming for all of us and, perhaps, slower in its effects.

Our major memory of that meeting five years ago is that Shahla and Jesus, as well as all other Action Group members, were pledging their support in helping with what seemed like the overwhelming magnitude of the task. We vividly remember the power of the reliable alliance—the solidarity of our Action Group's support. We were not going to be walking a lonesome valley of problem resolution by ourselves. We remember the feeling of comradeship—the eureka insight that we truly did have a reliable alliance of others who would walk with us, arms linked together, for whatever time it took, over however many hills were in front of us, to eventually reach a point where vision and reality would meet.

So we set out to begin to implement positive behavioral support through all the different steps that we have already described. Attending to all of these tasks was more than three full-time jobs, and yet everyone in JT's Action Group had multiple other responsibilities. Unfortunately, many families get so overwhelmed by what needs to be done that they give up on doing much of it at all.

A highly supportive aspect of the Action Group for us was that as parents we did not have to initiate, plan, and implement all of these supports and activities ourselves. With two jobs where we each work more than full-time and with two other children besides JT, not to mention our other roles and responsibilities, it would have been too overwhelming for us to have created JT's inclusive adult lifestyle on our own.

Rather, working over about a three-year period with the help and contribution of every single Action Group member, significant progress has been made with all of the tasks. Yet eternal vigilance is still required for continued skill development, monitoring, and recycling. One of the unique characteristics of Action Groups in terms of problem solving is that key people are there from 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, the facilitator summarizes the specific steps that need to happen before the next meeting and a designation of who is responsible. Every member of JT's

Action Group leaves with at least one task to accomplish; thus, approximately 8-10 different tasks can be accomplished without anyone feeling overwhelmed.

Celebrating Success

One of the unfortunate aspects of many traditional team meetings is that there is rarely ever an opportunity for celebration. The atmosphere typically tends to be somber and serious. A key aspect of Action Groups, on the other hand, is to take every occasion for celebration to affirm progress, allow and encourage gratitude, and set aside time to party rather than to always problem solve.

One way to celebrate is to have parties, and that is something that we have done frequently over the last six 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.



A second way to celebrate is to share stories with group members of how far JT has come over the last 5-6 years. Because many group members have joined since the really dark days in JT's life, we seek opportunities to reflect on some of the stories that particularly highlight progress and reasons for celebration.

The other aspect of celebration is to occasionally take opportunities at meetings to go beyond the ordinary to affirm the power and contribution 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 the family lights were the only ones 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 everyone working together 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. The send of reliable alliance that every single group member experienced through that celebration defies our ability to describe.

Implications

Action Groups are obviously not a magic solution. What works for one family cannot be expected to work for every family. But we do suggest to you that Action Groups offer a process—inviting support, creating connections, envisioning great expectations, solving problems, and celebrating success—for personalizing individual and family support. If this approach sounds possible for you, we encourage you to implement it with the individual to whom you are most committed. There is not a single recipe for Action Group, but rather many ways to tailor this process according to the particular situation.

One of the most successful aspects of the Action Group for us has been a consistent feeling of synergy within the group—a powerful sense that the whole is truly greater than the sum of the parts and that the group energy and creativity supersedes what any individual could generate alone.

The concept of synergy is hard to put into words. It might be helpful for you to reflect on times when you have been in a group of people in which you truly felt transformed from your individual ability to create change to being part of a movement or wave that is unstoppable. That rush of possibility and empowerment is a renewing experience and one that truly transforms great expectations from visions into lifestyle options. 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.

