

family

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Abstract

Anne and Rud Turnbull of the Beach Center on Families and Disability at the University of Kansas have a child with a disability. Their article includes a quote by Margaret Mead - "never doubt that a group of committed people can change the world. Indeed, it is the only thing that ever has" - which captures the essence of their family's story which they tell about a group of committed people who changed their world. **Keyword: Families**

Group Action Planning (GAP)

Our lead article describes empowerment, as a developmental process that combines motivation, internal skills, and external resources to cause desired changes to take place. There, we illustrated empowerment by two fictional families. Here, we want to describe how our very own family achieved empowerment and how our experience has laid a foundation for new research initiatives at the Beach Center to help empower other families.

Remember what Margaret Mead once said? "Never doubt that a group of committed people can change the world. Indeed, it is the only thing that ever has." That captures the essence of our family's story. A group of committed people changed our family's world and could change yours, as well.

A Vision of Empowerment

We vividly recall six years ago when our family was in disarray. At that time our son, Jay, was 19 years old. Like all high school students with moderate to severe intellectual disabilities in our community, he was headed to a sheltered workshop and a program of community group homes, or he was bound to stay at his family's home. That was not his or our choice, but it was just the reality. At that time, there was almost no supported employment in our community and certainly no one with his particular support needs who had pursued independent living.

He found both the workshop and group homes to be disempowering environments, and his expression of dissatisfaction was manifested in extremely challenging behavior. Sad to say, and despite trying, the existing programs were not capable of making the changes necessary to accommodate him. We had a vision of a life characterised by inclusion and meaningful relationships. Regrettably, most

of the secondary education and adult service providers thought we were totally unrealistic. Bottom line: We knew we had no choice but to pursue our vision. So we left the system with its services and entitlements, and gathered a small group of people together to change our family world.

The Vision Becomes Reality

Now, six years later, our vision has come true. In fact, we have far exceeded our original vision and keep working to create a more empowered life for Jay and for ourselves. Today, as a result of our "unrealistic" vision, Jay:

- has a mortgage on a house that he is buying - his very own "place," with his name on the mailbox, giving him the freedom to be there according to his own preferences and tastes,
- has a 30 – hour per week job as a clerical aide at the University of Kansas, working with caring and supportive co-workers,
- has roommates who are his friends, not his staff, who provide support and companionship in a personalized, respectful, and enjoyable manner,
- has a whole host of friends who participate in a wide range of activities, many around his major interest of music, but also including working out, making dinner, going over to friends' houses, and participating in many other community activities, and
- is in his fourth year as an honorary member of the Sigma Alpha Epsilon fraternity, where he engages in a variety of activities with other members.

How did this radical change occur? Not easily, and not quickly. But it happened to us, and it can happen to you.

Making Radical Changes

Basically, we gathered together a group of caring friends and professionals and sought to create an empowering context where visions could be shared and action plans created to implement those visions. Over the last six years, this group has worked with us, as a "reliable alliance," being there in good times and bad, to always take the next step to create Jay's desired lifestyle. We refer to this process as our "action group." Five key attributes have made it successful.

Inviting Support

We explicitly invited friends, professionals, and extended family to help support us. We had to let them know exactly what we needed. That was not too hard, because we knew all we had to do was open ourselves up (and surrender some of our privacy) to others. Although we had lived in our community for six years before starting our action group, we had rarely ever let people know what we needed to support Jay. Of course, sometimes we felt sad that people did not offer to help. But, we asked ourselves, how could they know what to offer unless we first asked?

Thus we took the initiative; identifying people whom we thought could help our visions come true and specifically inviting them to be part of the action group. Surprisingly, no one declined our invitation. Indeed, everyone not only met our hopes but also exceeded them. To our astonishment, we discovered that we had always been surrounded by an invisible resource, one that, although dormant, was easy to activate. All it took was a direct request. We even had many people tell us how glad they were that we let them know how they could help us, because they had always wanted to but did not know how and did not feel comfortable bringing it up.

Bonding

Although we had been to many individualised planning team meetings for Jay, rarely in those meetings did we truly feel emotionally connected to others there. Rather, people seemed to operate more as individuals rather than a collective alliance.

In our action group, over the years we have found it absolutely essential to develop, to the greatest extent possible, reciprocal, caring relationships. We sought for everyone see his or her critical role and contributions, to know that those were appreciated, to feel inspired by the progress that Jay was making, and, most importantly, to be cared for and about. This action group, we learned, encircled not just Jay but everyone there. Here's the very simple point:

Action groups must create a reliable alliance for every single member. They must offer a cocoon of friendship; confidence that each member will "be there" for each other, and a sense that the support is not fleeting or temporary.

Vision

None of our efforts to invite support and create a reciprocal; caring group would have mattered if we had not had a vision for our family. That vision was this: Life tailored to Jay's preferences, first and foremost, and to his family's, next in order. It was one thing for us to have a vision, but altogether another for us to share it and for the group to "own" it.

Our mission to have everyone in the group to own that vision, to believe in it and know that it could happen with their help, was not hard to achieve. First, we excluded those who were nearsighted and lacked vision or disagreed with our vision. We tried to foster a spirit of "what-if-ness," beating the odds, and pushing the limits of what is possible. We also found that vision is an ever-evolving

process. As we accomplished our initial vision, we found that our vision kept expanding and growing in positive directions.

Systematic Problem Solving

Inviting support, creating a caring and careful support circle, and having a shared vision would not have helped a bit unless we had been willing to do systematic problem solving together. To problem--solve means carefully delineating preferences and needs, brainstorming a whole range of diverse options, evaluating each option in terms of the pros and cons, making an informed decision on the most promising option, developing a specific plan of how that option will be implemented, and doing ongoing evaluation to see if desired outcomes are being achieved.

This kind of systematic problem solving process had been missing in our lives, and the result was, predictably, that the visions were eluding us. We also had experienced another type of breakdown: All the talk about wonderful and promising ideas was just that. There was inadequate logistical follow-through to put those ideas into place and to ensure their success. We found that the actual action group meeting is vital, but what happens between meetings in terms of concrete, practical, daily follow-through is absolutely essential. Implementing plans requires technical skills, interpersonal dynamics, and careful logistical management.

Celebration

Throughout the process, we found it absolutely essential to set aside time to celebrate progress and to celebrate our reliable alliance with each other. Far too many group meetings are sombre, serious planning sessions called specifically and only to address some need or problem. Thus, we got together many times to "just party." These celebrations cemented the group bonding, renewed our and

others' energy and motivation, and reinforced follow-through on our action plans.

Here is the text that Jay dictated for an invitation to one of the parties:

Dear People:

Will you come to a party at my house? Tom and Lillie are my roommates. Dear friends, will you meet Tom and Lillie.

Bring food, like cake and ice cream or cookies or bananas or watermelon or chicken or hot dogs or hamburgers or pie or nectarines or cucumbers or carrots.

I'll bring the pop and M&Ms.

Dear people, bring friends.

Love, Jay

Beach Center Contribution

Through the Beach Center, we are exporting our own action group experience and carrying it out with other families. This fall, we have been doing group action planning (GAP) with a family with four children, one of whom is 15 years old, has cognitive and behavioural challenges, is physically but not socially included in high school, and deeply wants to be included in such activities as sports and dances.

We are also carrying out a self-determination research and model demonstration project through Full Citizenship, Inc., the Beach Centre's non-profit affiliate. That project, which employs a young adult with mental retardation as a staff member, uses GAP as a technique for carrying out the visions of high school seniors who have developmental disabilities.

We are also just launching GAP as a part of the Kansas State systems change grant for transition. Furthermore, we are in the process of writing a manual on specific steps for implementing GAP. (The manual will be available in March. If you are interested in knowing more about GAP and

receiving a copy of that manual, drop us a line.)

Never Doubt Your Power

We take to heart Margaret Mead's admonition about never doubting the power of a group of committed people. We know firsthand how it has changed our lives. At the Beach Center, we are committed to research and training that will teach us more about GAP and help us share our knowledge and enthusiasm with others.

Don't get us wrong: We are not advocating any retreat from the individualised "I" plan (IEP, IFSP) that Jay and others have as a right. But more is required than an "I" plan, however important that type of plan is. The "I" plan-approach most certainly is necessary. The problem is that it is not sufficient. It did not allow for, and certainly did not encourage, the strategies of inviting support, bonding, visioning, problem solving, and celebrating. GAP seems to fill the gap between the ideal of the "I" plan and the reality of its implementation.

For our family and we hope for many others, GAP will be more than sufficient. After all, it convenes the "group of committed people" of which Margaret Mead wrote, it calls upon them to "change the world" from the bottom up, and, for us, it has been "the only thing that ever has" changed our world and perhaps yours, too.

Give it a try: You have nothing to lose and everything to gain.

- Ann and Rud Turnbull ■