



*EMERGING “LIVES OF DISTINCTION” AT
ULSTER-GREENE ARC: STEPPING OUT OF
THE ORGANIZATIONAL “COMFORT ZONE”*

A Case Study in the Organizational Transformation Series
from the Center on Human Policy

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INTRODUCTION

The Ulster-Greene Arc was established in 1958 and grew most notably in the 1970s and 1980s, in the era of deinstitutionalization. The Arc serves almost 1,500 individuals with developmental disabilities in Ulster and Greene counties in New York State. For the past 12 years, they have been engaged in a multifaceted approach to organizational change in order to improve the quality of lives of people they support.

This report describes some of the strategies for organizational change used by Ulster-Greene Arc. In particular, the intent of this report is to document steps toward change by an organization that grew into a very large, traditional organization. It is based on a 2-day site visit in March 2010, and does not reflect any changes that have taken place since that time. All names used throughout this report are pseudonyms.

Background

Over time, the Ulster-Greene Arc grew into a large, continuum-based organization, offering an array of services from individualized, in-home supports to numerous large group homes and day habilitation centers. In 2010, in residential services, they supported 255 people: 1 person who owned their own home and shared it with two other individuals who are supported by the organization; 24 people who rented their own apartments; 25 people who lived in apartments in two buildings owned by the Arc composed of apartments for people supported by the organization; 13 people who lived in apartments rented by the Arc; and 160

individuals who lived in group homes ranging in size from 3 to 12; and 30 individuals who lived in 3- to 10-person homes specially for those who are medically frail. In employment/day services, the organization supported 780 people: 180 in employment (70 of these in enclaves and 110 in individual placements); 320 in prevocational services (200 at one location, 60 at another, and 60 at a third) and 280 in day habilitation centers (150 at one location and between 10-25 people at 6 other locations). According to staff, two of the overarching themes about the organization's past are: there was a history of patriarchal management, in which all decisions went to the top; and there was a mindset of control over people. As one staff member commented: "People have lost sight of why they are here; it's not to control people."

In 2002, the current director was hired based on an organizational recognition of the need to improve the quality of people's lives. In 2003, they launched a "positive behavior supports" initiative, with the focus on enriching people's lives in order to help them avoid negative behaviors, rather than just reacting to behaviors. This initiative included identification of four core organizational values—respect, integrity, compassion, and excellence—and efforts to imbed these values in the organization. This involved change in many aspects of the organization, including:

- Training a significant number of staff on positive behavior supports
- Providing increased coaching and mentorship for direct support staff
- Increased recognition of the efforts of direct support staff through Everyday Heroes

- 360 degree assessments of managers in order to incorporate feedback from direct support staff among others
- Revised job descriptions
- Revised hiring process and orientation
- Re-established a Behavior Rights Committee in order to challenge the cases and not just rubber stamp the recommendations
- Establishment of a senior team to assist staff with ideas and problem solving around support issues in order to avert a crisis
- Improved communication between administrators and staff across departments

According to administrators, this positive behavior supports initiative had a positive impact. One indicator of this impact was that the number of behavior plans dropped dramatically. In the early 2000s, 35% of people had behavior plans, and by 2010 less than 1% of people had behavior plans. Additionally, in 2000, the employee turnover rate was 27%, and in 2009 it was 15%. However, in the midst of this improvement, in 2006, the organization faced a limited fiscal review by the state. This temporarily diverted their attention away from the focus on quality lives.

Again, in 2008, they turned significant attention toward improvement in people's quality of life. Although behavior plans and turnover had been reduced by previous efforts, administrators at Ulster-Greene Arc realized that there was still significant work to do in this area. They recognized the need to work at change on both the individual and organizational levels.

A first step was to reframe the mission of the organization. The mission is: “To offer people with intellectual and other developmental disabilities opportunities to live and experience full lives.” They recognized that the culture of the organization was still oriented toward an expectation of mediocrity. In light of this, they began exploring the idea of assisting people to live “lives of distinction. “ According to Beth Mount, “*Lives of Distinction* puts forth the vision that every person with a disability has a distinctive contribution to make to the world. When we discover and develop these contributions, and make connections between people and places in the community, these contributions become visible, and people’s lives are enriched. Consequently, people with disabilities are no longer seen as ‘different.’ Instead, they can live lives of distinction, as people admired and respected by others” (Mount, 2007).

Strategies for Change Toward “Lives of Distinction”

An overarching organizational strategy for change has been to take advantage of every possible opportunity to learn from other individuals and organizations about ideas for increasing their capacity to provide person-centered supports. During the latter part of 2008 and 2009, staff from Ulster-Greene Arc engaged in three different types of experiences designed to assist them to learn about promoting change at the individual and organizational level. Awakening the Spirit was a two-part event sponsored by Onondaga Community Living. The first part, in September 2008, was designed to offer providers strategies and examples related to promoting person-centered lives for individuals with developmental disabilities. The second part, in June 2009, engaged providers to begin planning with an individual from their organization. Then, in September 2009, the agency contracted with Beth Mount and

Hanns Meissner to lead a two-day retreat which would encompass the beginning of person-centered planning for nine individuals from the organization along with their circles of support. Finally, between October 2009 and June 2010, a team of staff from the organization participated in the NYSACRA Learning Institute, co-led by Beth Mount, Hanns Meissner, and John O'Brien. The objective was for each organization to "develop its capacity to provide individualized supports." Among other experiences, this included time for reflection and discussion about the organization and potential opportunities and strategies for change, learning from the facilitators and guest consultants, and learning from visits to other organizations.

Based in large part on what they have learned from these experiences, as well as from past organizational initiatives, they have implemented a wide array of strategies designed to promote organizational change that facilitates quality, person-centered supports. Some of these strategies include the following:

Strategic thinking. While the senior management team meets regularly, the director realized that "this group was not working well in terms of driving the strategic structure." She pulled in others to join this team, including representatives of key operations and departments within the organization, as well as others in the organization whom she identified as "strategic thinkers." Additionally, the director intentionally shifted the leadership and management approach from one that had been "patriarchal" to one that was more team oriented. As she put it, "Before, it was all me, all resting on my shoulders, and the weight of the world was insurmountable." The director and this team committed to look across the organization to see what needed to be changed to promote individualized supports, and

charged each of the department directors with developing goals related to working toward lives of distinction. As part of their strategic planning, she has challenged this group to consider the idea of new services without new buildings. Further, she appointed one of the associate executive directors as having oversight into operationalizing individualized supports within the organization.

Within this strategic thinking group, the director has intentionally set aside time for in-depth discussion about issues and ideas, and she has set a tone of openness and flexibility. As she put it, “Any idea is welcome.” This group discusses many topics, such as organizational values and practice, ethics, dilemmas with regard to promoting individual control, dilemmas regarding balancing the desire to be creative with the need to meet regulatory requirements, and so on. As one means of promoting dialog, this group has used Visual Explore as a tool to promote in-depth conversation.

Restructuring for Integration and scale. Within the central management of the organization, the director noted that “We do lots more cross-departmental work, like pulling in HR, where we wouldn’t have before.” Additionally, they have begun using Therap[®] in order provide more “real-time” data as well as to integrate data from across the organization. While there has been some effort to work across departments, administrators recognize that throughout the organization there is still significant separation between residential and employment/day services. Since the organization is so large, and spread over such a wide geographic area, they are working on dividing the organization into six “pods,” or smaller units. Within the pods, they envision having staff from employment/day services and residential work collaboratively.

Staff training and development: Toward positive, collaborative relationships.

Currently, according to administrators, a core group of staff who have taken part in person-centered planning and learning circles are excited about the organizational change toward lives of distinction; at the same time, as one administrator noted, “the rest have not bought into it.” Administrators are taking several steps in an attempt to promote further staff investment in person-centered supports. Several years ago, the organization began having discussions with staff about the importance of assisting individuals with disabilities to have power and control, rather than exerting control over them. Administrators felt that this was helpful, but that something more was needed. As one administrator put it, “It can’t be a PowerPoint forever. We are working on making it more interactive, with more dialogue, to bring them in and engage them.” In addition, they are making an effort to hire staff who are engaging and creative. When staff are first hired, each spends a day as someone receiving services would, in order to get a feel for the experiences of people with disabilities within the organization. Additionally, since assisting individuals they support to form community relationships is a priority for the organization, there is an emphasis on encouraging staff to form positive relationships with the people they support and on training all staff about strategies for fostering relationships with others. In the past few years, administrators report that they are witnessing increasing examples of staff who, having formed a close relationship with an individual, break some of the traditional boundaries and go skiing together on their own time or invite someone to a family or neighborhood gathering. Telling these stories is an important vehicle they use for shifting the agency culture. Finally, administrators have recognized that if they want a change in staff, they need to change the supervisory style. One

administrator noted, “There is a fear mentality among staff. They treat people the way they are treated by their supervisors. People are controlled and told what to do, and fear is used. This happens for staff, and for the people they support.” Administrators are working with supervisors on creating a positive working environment and, in particular, on spending more time mentoring and coaching staff. Further, administrators are spending time examining their own practices and relationships with supervisors and direct support staff, so that these relationships reflect the organizational values. One strategy for doing this has been use of 360 degree assessments, which include input from direct support staff regarding the role of the administrators.

Creating Positive Examples

For any organization engaged in change, it is important to work on creating a growing number of examples of individualized support. This can help everyone—including staff, administrators, people with disabilities, and family members—learn about the strategies and possibilities associated with individualized support. A few of the recent examples that are emerging at Ulster-Greene Arc include the following:

Joe¹. Joe and his circle of support came to the Skytop retreat. At that time, Joe was working in a sheltered workshop and living in a group home of eight. In discussions with his circle, it became clear that looking for work was a priority for Joe. As a circle member put it, “Joe was regressing in the workshop.” His father felt strongly that an enclave was not the answer. Circle members knew that Joe enjoyed manual labor. One circle member knew a

¹All names used in this report are pseudonyms.

woman who has four horses and needed assistance to care for them. In November 2009 Joe began volunteering at the horse farm. He assists in grooming the horses, and is learning about various equipment and procedures associated with this. The circle was struggling with trying to figure out how to pay Joe for this work. Joe opted to begin as a volunteer, rather than wait until the pay was figured out. Joe's father and other circle members agree that "Joe is capable of much more, and that this is just a start." Additionally, in time, Joe is interested in the possibility of moving into his own apartment. In reflection, Joe's father feels that the biggest thing that has come out of the process thus far is that there is now regular communication among Joe and the members of his circle, and that this creates a positive platform for continued work assisting Joe to achieve a life that is desirable and meaningful to him.

Mark. For 13 years, Mark lived in a certified apartment operated by Ulster-Greene Arc. He and his support circle went to the Skytop retreat. There, they talked with Mark about his desire to one day own his own home. He decided that one step in that direction would be to rent his own apartment—an uncertified apartment, not licensed by the agency. Mark moved into his own apartment in September 2010. Here he feels a greater sense of control and ownership than in the previous apartment. For instance, he made the decision to share the apartment with his girlfriend for a few months, then later made the decision to live on his own again after that arrangement did not work out so well. His circle meets every 2 weeks to help him continue planning for the purchase of his own home. Additionally, while Mark has worked at a supermarket for 16 years, he would like to also further pursue his interest in music, possibly by doing some music recording. In order to explore this, circle members have

been accompanying Mark on visits to places such as a recording studio and a radio station. While Mark has benefitted from the work of the circle, other circle members have been impressed with and appreciated the process as well. As one commented: “It’s been wonderful to have the opportunity to do this, with everyone really getting to know what Mark wants, and understanding why, and everyone working together, as opposed to one person doing something off here, another doing something else over there.” Another circle member reflected: “This process has been refreshing. We have seen the importance of mapping, of really seeing his background. With other people, in the past, we made more surface changes. But this has really been different.”

Greg and Brenda. Greg and Brenda came with their circle of support to the Awakening the Spirit conference sponsored by Onondaga Community Living. The objective of this conference was for teams to engage in person-centered planning that would continue beyond the conference. At that time, Brenda was living with her mother, and Greg was living in a certified supported apartment. They wanted to get married and move into their own apartment. Following the conference, the support circle members assisted Greg and Brenda to get married and move into their own uncertified apartment. Staff from the organization are doing job development with both Greg and Brenda. In regard to their life today, one circle member commented: “They are doing well. They have their ups and downs. It’s not a fairy tale, but it’s a life in progress.”

Future directions. In addition to the above examples, the organization has multiple initiatives in various stages of planning and implementation that should eventually increase community membership, participation, and quality of life. The Renaissance Program opened

in April 2009. It began with 3 people, and is up to 7 now. The program is designed for individuals with autism who have been challenging to support due to behavioral issues. The program aims to engage participants in meaningful activities, including work, art, music, leisure, and more. The program is intentionally small, with a high ratio of staff to participants. Staff are encouraged to be creative, “make mistakes and learn from them,” form relationships with the people they support, and utilize community places and settings for activities. Additionally, staff work collaboratively with other people in the person’s life, such as family members or group home staff. As one administrator reflected: “This is a way of pushing people out of their comfort zone. This will help show by action to staff what difference this approach can make. Then, after we learn how, we can do more of this.” While the activities that are part of this program currently take place primarily within the facility, the vision is that there will be expanded use of the community and that the experience gained from this will be key in increasing the capacity of staff and the organization as a whole to support individuals in community settings.

There are also plans to focus on taking apart a 10-person group home. A first step is working with staff to begin to get to know people well, plan with people, and assist people in developing community connections. In this process, administrators are encouraging supervisors to shift the conversation with staff from a focus on “what is not working,” to a focus on “what works.” Additionally, in the near future, there are plans to investigate community partnerships that might lead to increased community housing opportunities. Finally, there are plans to reduce the number of people in facility-based employment by 10%.

Lessons

Based on their work, they have learned a number of lessons related to organizational change. These include:

- The importance of creating and utilizing opportunities within the state context. In order to create opportunities at the organizational level, it is important not to rely on or wait for the state, in order to institute change. At the same time, it is important not to just take “no,” for an answer from the state, but to cultivate an ongoing relationship and be prepared to negotiate; as one administrator put it, “You won’t get everything you want. And, you have to keep going back.” Additionally, it is important to take advantage of the opportunities that are offered by the state. For instance, by the time portal funding that would promote self-direction and self-determination was made available in New York State, the Ulster-Greene Arc had already prepared several proposals; as a result, they obtained 8 of the 11 portals in their region. Second, they have utilized funding from the state that enables them to pay a person’s salary for 2 months at a new job.
- The importance of being open to new understandings about the nature of individual change. They have noted some dramatic personal changes in the lives of people who are being supported in individualized ways. In an organization that, in the past, has been oriented toward skill development, this has led them to reflect that, as one staff member put it, “Sometimes it’s not so much the focus on skills but creating a different environment that makes a difference in people.” They have also learned that promoting person-centered individual change requires

ongoing work; without long-term effort, the possibilities for significant change can be limited. Further, they have learned that, within the circle of support, it is helpful to have a designated “champion,” to coordinate the work of the circle. Finally, they have learned that person-centered individual change requires ongoing vigilance about “thinking outside of the box.” Otherwise, it can be easy, and more comfortable, to slip back into traditional responses. For example, when assisting someone to plan for a move from a group home, the traditional move might have been to the agency-operated apartment building. However, organization staff are challenging themselves to think of new and creative options.

- The importance of tracking change in terms of assessment of quality, in addition to measures such as behavior plans and staff turnover. The organization has experienced significant decreases in behavior plans and in staff turnover over the past 10 or more years. These are notable indicators of change in the organizational culture. At the same time, they are committed to increased assessment of the quality of people’s lives, through multiple means including surveys and personal interviews, as another way of tracking organizational change.
- The importance of guiding organizational change based on work toward individual change. The focus on guiding organizational change based on person-centered work with individuals has been helpful to their change process. One administrator reflected that past change efforts did not include this same emphasis on learning from individual change.

- The importance of participation in the Learning Institute and, in particular, learning from other organizations that have worked on change. According to an administrator, participation in the Learning Institute “provided a structure, form, and discipline to keep us on track.” Additionally, one of the key aspects of the Learning Institute for participants from Ulster-Greene Arc was visiting other organizations and being exposed to creative approaches to individualized support. For example, based on visits, they are considering the development of more day habilitation and pre-vocational services “without walls.” Additionally, they are considering owning less property, utilizing “paid neighbors,” and developing more uncertified settings.

CONCLUSION

As they have worked to foster lives of distinction the past few years, Ulster-Greene Arc has recognized the necessity for simultaneous work on organizational change that increases their capacity to provide person-centered supports. As one administrator put it, “It’s nice to have change for the individuals, but without changing the organization, it won’t stick or go far.” Further, as an organization that has operated with a highly facility-based, continuum-based model for many years, they recognize the need to “push themselves out of their comfort zone” if they are to truly support people in creative and individualized ways. Otherwise, as one administrator put it, “We may get too satisfied with what we are already doing.” At the same time as the work on individual and organizational change may be uncomfortable and challenging, the administrators and staff at Ulster-Greene Arc are

motivated and energized to continue this work as they witness the emerging lives of distinction in the people they support.

REFERENCE

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