The Seeing Is Believing Project: A "Lifeline" for Organizational Change in North Carolina

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

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August, 2010

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The preparation of this report was supported through a subcontract with the Research and Training Center on Community Living and Employment, University of Minnesota, supported by the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR), through Contract No. H133B080005. Members of the Center are encouraged to express their opinions; however, these do not necessarily represent the official position of NIDRR and no endorsement should be inferred.

Acknowledgement is made Mike Mayer and all of those involved in the Seeing Is Believing Project for assistance in arranging the site visit and in the preparation of this report, and Rachael Zubal-Ruggieri and Steve Taylor for their commentary and assistance in preparation of this report.

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INTRODUCTION

Seeing Is Believing is a project sponsored by the North Carolina Council on Developmental Disabilities (NCCDD). The project is a 3-year initiative, running from 2008-2010. The purpose of the initiative is to promote organizational change toward individualized supports within provider agencies in North Carolina. There is a special focus on helping people move from congregate care settings to their own homes, which can include shared living arrangements.

Based on national research, North Carolina has generally been making gradual progress decreasing the number of individuals in large facilities (e.g., 7 or more residents) and increasing the number of individuals in smaller settings and receiving Home and Community Based Services (HCBS) under the Medicaid waiver. At the same time, North Carolina lags behind the national average of people living in their own homes (ranked at 26) and in settings with 1-6 individuals (ranked at 31), and has a greater than average percentage of people in large state facilities (ranked 43 nationally) (Lakin, Larson, Salmi & Scott, 2009).

The Seeing Is Believing (SIB) project grew out of an international conference in Asheville, North Carolina, sponsored by the NCCDD. The conference focused on ways to direct organizational change toward supported living for all people "without exception," meaning without regard to the intensity of supports needed. As defined by John O'Brien, supported living is: a safe and decent home of your own; choice; personalized assistance; and support from others who care about and respect you (O'Brien, 1993).

Following the Asheville conference, the NCCDD issued a Request for Proposals for a project to spearhead a 3-year initiative to build provider capacity in relation to supported living. The grant was awarded to Community Resource Alliance (CRA); CRA then formed a team of consultants to provide training, technical assistance, and other resources. The intent of the project is to build provider capacity through redesigning organizational structures and functioning to enable organizations to shift toward supported living and inclusion of persons with special needs, rather than just creating smaller group homes. Four agencies were selected to participate in the project based on interest expressed following the Asheville conference. CRA made a deliberate attempt to select different types of organizations in order to be able to eventually demonstrate that organizational change to supported living is possible across various types of organizations, including large organizations that have historically had a strong orientation to facility-based services.

This report is part of a series of reports describing organizational transformation. Much of the information is based on data, interviews, and observations made during a site visit to North Carolina in January 2010. This visit included observation of a project meeting, and interviews with CRA consultants and representatives from the four agencies involved in the SIB initiative. The report first provides profiles of the four organizations involved in this initiative. Following is a discussion of the overall strategies of CRA to promote organizational change through the Seeing Is Believing (SIB) project, and the lessons that have been learned from this work.

ORGANIZATIONAL PROFILES

As part of the SIB initiative, four organizations have been engaged in work on organizational transformation that includes work focused on promoting individualized, person-centered supports for an initial group of selected individuals, as well as work that is focused on the organizational systems and structures. The SIB consultants helped facilitate individual and organizational PATH (Planning Alternative Tomorrows with Hope) planning processes (Pearpoint, O'Brien, & Forest, 1993) with the participating organizations. Additionally, the CRA consultants, in conjunction with other national consultants contracted by CRA to work on this project, provided each organization with training and technical assistance geared to that particular organization's needs and circumstances. Following is a brief overview of each organization, as well as a summary of some of the strategies they have used for change and some of the challenges they have faced.

RHA Howells

The Howells Company was formed 40 years ago, and initially focused on developing large-scale facilities around the state. They continue to operate a number of these, including three with more than 100 people, two with 30 or more people, and one with 15 residents. The organization has also developed smaller facilities, typically 6-bed group homes. In 2004, Howells merged with RHA to become RHA/Howells. In recent years, the organization has shifted from 99% facility based services to 50% "community supports" and 50% "institutional scale" large ICFs/MR. They have been attempting to "downsize" facilities; they are actively seeking ways that will make it possible for all new services to be community-based services.

Their participation in the SIB project has helped them identify and work on some additional, specific steps toward more individualized supports. RHA/Howells has engaged in several different initiatives throughout the organization to improve the quality of the person-centered plans and to improve "meaningful day" activities and social engagement, including fostering the development of a co-op where current residents can make and sell their own products. One of the key initiatives is targeting a 15-bed facility for closure. This initiative and some of its components are described below.

Targeting a 15-bed facility for closure. Based on their organizational PATH planning, administrators decided to begin working on facility closure by targeting a 15-bed facility in Greensboro for closure. Residents of this facility include some individuals who have significant and multiple disabilities, as well as complex health care needs. Administrators of this facility feel that the experience implementing closure will give the organization as a whole important experience in designing community supports for individuals with severe disabilities. Also, they maintain that once some individuals have moved to community settings, this will provide other staff, families, and individuals with disabilities a clearer picture of the possibilities of community living for all individuals. As part of the work toward closure, a number of steps have been taken. These include:

- Person-centered planning for a few initial individuals. As a first step toward facility closure, staff at RHA Howells are conducting person-centered planning for a few initial individuals. Just as plans were being completed for one woman, she developed very serious health issues, and had to move to a health care facility. She returned to the RHA Howells facility in the late winter of 2010. Plans are

accelerating so that shortly she will be able to move to a shared apartment in the community.

- Form self-advocacy groups. People living in facilities operated by RHA Howells have historically had little or no access to self-advocacy. With assistance from SIB consultants, in particular the self-advocacy consultants, a self-advocacy group has been established at the Greensboro facility and additional efforts are underway to promote self-advocacy among those who are supported by RHA/Howells throughout the state. There is recognition that, over time, these advocacy groups will assist individuals with disabilities to connect with self-advocacy initiatives that are also independent of service provider agencies.
- Develop opportunities for community employment and more meaningful daytimes. Agency staff are working in partnership with a Work Force program to create community employment and volunteer opportunities for the individuals at the Greensboro facility. Additionally, through the SIB project, a national consultant assisted with the development of microenterprises for some interested individuals. Currently, these are based at the facility; a next step will be finding opportunities for the establishment and support of microenterprises in community settings.
- Design a new approach to staff training. Based on PATH planning, administrators recognized that a key to organizational change lies in the development of a new approach to staff training. Many staff have been with the organization for several years and are, as one administrator put it, "good caretakers." However, there remains a critical need for staff to learn how to better support people as they

move toward greater independence, self-sufficiency, and the establishment of meaningful relationships with others in the community.

- Assist people to spend more time in community places. RHA Howells has made concerted efforts to connect people to the broader community. As one indicator of this, agency administrators are working with direct support staff to ensure that people spend a portion of their personal monies a community businesses and other establishments. As another potential means of assisting people to spend more time in community places, the organization has applied for a grant that will focus on the establishment of relationships with community members.
- Guardianship reversal. Guardianship is routinely assigned to anyone who has been placed in a state operated facility for people labeled with intellectual and developmental disabilities (IDD). Staff at RHA Howells are working to assist individuals in gaining legal control over their lives.

Challenges. RHA Howells faces some significant challenges in shifting to individualized supports, particularly as they are a large organization that is heavily invested in numerous large and small facilities.

- Facility divestment. RHA Howells owns and operates a substantial number of large and smaller facilities. Thus, even with the technical assistance from the project, divesting of their facilities will be a challenging, long-term process requiring significant organizational commitment, and the cooperation of both state and federal entities (such as HUD).
- Establishing supports for people with significant disabilities in the community. As

there are few examples in the state, and funding does not provide incentive for this, staff and administrators have a difficult time envisioning how to support individuals with complex medical needs in the community. This will require collaboration with other state entities, funding incentives, and technical assistance provided by national experts from places where all people are supported in the community.

- Parental fear about the stability of nonfacility-based, community options. According to administrators, some parents are fearful that CAP (and the related MFP) funding is unstable, and such funding instability may result in inadequate support for individuals who rely on these funding streams to move to individualized community settings.

Ralph Scott Lifeservices

Ralph Scott Lifeservices (RSL) was founded in 1971 by a collective group of parents of, and advocates for, children with developmental disabilities. The organization serves approximately 150 individuals in the Burlington, North Carolina area (e.g., Alamance and Caswell counties). In the early years, the organization focused on the development of facility-based residential and day services. However, in more recent years, there were efforts to shift to smaller facility-based services and to develop alternatives to facility-based services. For example, they began limiting the size of their group homes to six people, and a range of services were offered that could support people in their own homes and apartments. This progressive shift toward more inclusive services was undertaken without a strategic plan or

specific direction. As a participant in the SIB initiative, RSL has taken the following steps toward organizational change:

- Develop a new vision and plan for the organization. With assistance from the CRA consultants, an organizational PATH was completed that gave important direction for future growth and organizational focus. This organizational PATH was adopted by the board, and has become the strategic plan for the organization. This plan focuses on moving away from facility-based services to more individualized services. While this initiative has at first focused on the residential services department of the agency, staff from other departments became enthusiastic about what they had observed and expressed the desire to be included.
- Develop an "enlist everyone" approach. Teams of Change were developed to incorporate ideas from the PATH to action. These focused on the areas of: community, staff development, and staff recognition. This involved administrative personnel, direct support staff, and individuals in supported employment. Each team worked for a year to develop ideas in a formal presentation and have continued working together to use these ideas to develop practice. These teams have become an integral part of the overall organizational Quality Improvement.
- Review and revision of policies and procedures to match with a shift to person-centered thinking. Among the areas being reviewed in collaboration with CRA are alternative staffing and support arrangements, including shared living and enhanced in-home supports.

- Focusing on offering choices and strengthening natural supports. First steps have included expanding relationships with local management and funding entities (LMEs) and obtaining memorandum of agreements to provide supports to more people.
- Reorganizing and expanding Community Services. The Community Services department will have the primary responsibility of developing and supporting all new services in the community. The overall reorganization developed from the agency PATH and also included hiring a development manager to strengthen fundraising efforts and community relationships.
- Initiate interdepartmental staff collaboration. In order to implement the individual and organizational changes, administrators realized that staff would have to work together in new ways, working across traditional teams and departments.
- Conduct PATH planning for four individuals. Person-centered PATH planning has been conducted for four individuals supported by Ralph Scott Lifeservices. For example, Theresa[1] is a young woman who just graduated from high school, works at the RLS office, and lives in a group home. Prior to the person-centered planning, Theresa did not realize that having her own home was even a possibility. Now that she has become aware of this possibility, she would like to pursue this option. Additionally, she would like to get her driver's license. As part of the steps in working toward living in her own home, Theresa must become a U.S. citizen and then obtain Medicaid waiver funding, so she is currently working with her staff and

[1]All names in these accounts are pseudonyms.

circle of support on this. Significant planning has also been accomplished with two young men, Greg and Larry. They both live in an ICF, but would like to share a home. At first their families were apprehensive, but they have now become supportive of this idea. There is a house that was donated to the agency, and the plan was for Greg and Larry to rent this house. However, recently there have been cuts in the state IPRS (general revenue) funding; due to these cuts, there is not sufficient money for Greg and Larry to make this move. Despite some setbacks, the individuals who have participated in person-centered planning have been very energized by the process. As one staff commented, "They all have their PATH's on their walls." Agency staff are committed to continuing to work toward finding a way to assist Greg and Larry to move to their own home.

- Develop new individualized services. As services are being developed for new people coming into the agency, the intent is to create individualized services rather than facility-based or group-based services. As the organization works to develop the individualized supports they have recognized the need for "crafting a life," as opposed to just looking at segments of people's lives. Thus, while assisting people with supports for community living, additional efforts are focused on building micro-enterprises and enhancing community assets to build a life without walls instead of a traditional facility based day service. One staff person, who has been part of the Seeing Is Believing coalition, has primary responsibility for the development of these new services.

- Actively practicing the techniques learned at an Asset Based Community Development training. This has resulted in many positive outcomes including new relationships with a local university to enlist mentors and volunteers and with a local assisted living agency to offer community based support collaborations.
- Training all staff on the new application of person centered thinking as part of a collaboration with other agencies. RSL was able to barter training and assist another SIB participating agency with their PATH. The development of these types of relationships aligns with CRA's intention, as part of this project, to assist agencies to build partnerships and collaborations that can enhance community capacity.

Challenges. Financing for services is the biggest challenge currently faced by RSL in the development of individualized supports. The agency has only been getting 47% of the cost of services for many people they support with IPRS funding, and recently they have experienced an additional 14% cut to that funding. Staff and administrators recognize that there are an increasing number of vacancies in group homes because "that's not what people want that much anymore." At the same time, staff are frustrated by the financial challenges and time-consuming process of trying to assist people to live in more individualized settings. Due to this frustration, there is the temptation to fall back on older ways of serving people who are in need of support services, such as the use of an apartment building exclusively for multiple people with disabilities, rather than helping those individuals live in many different locations, and finding other nondisabled community members to live in the apartment building alongside a few who have disabilities. However, both staff and administrators recognize that

the direction they really want to move toward is one of promoting inclusive community life rather than segregation. The SIB coalition consistently provides support to uphold this vision.

Charles Hines and Son, Inc.

Charles Hines and Son, Inc. was founded in 1996 by the parents of a son with autism. According to an administrator, the organization's founders had experienced difficulty finding and retaining staff who were "trained, committed, and paid enough to reliably support their son." This need led Andy and Anne Hines to establish a small, for-profit provider agency offering services in a discrete locality, with an emphasis on hiring and cultivating professional, committed staff. The organization does not own and operate residential facilities but supports people to live with family or in their own homes in the community. The company has encouraged self-determination and always supported people to choose the staff they wish to support them. One administrator reflected, "At first we were not sure how we would fit into an organizational change initiative that encouraged people to live in their own homes since most of our consumers are already in such living arrangements; then, we realized, while we support people who live at home, some of them are very isolated from the community." Some of the steps and strategies Charles Hines & Son, Inc. has used as a part of the SIB project to foster change and increase community inclusion include:

- Revise staff training and recruitment. All staff participated in person-centered thinking training; consequently ongoing direct-care staff training now incorporates a greater emphasis on identifying and using strategies to assist people in establishing community connections and increasing participation and inclusion in

the community. When hiring new staff, the organization looks for employees with skills related to assisting people in these areas.

- Create a special initiative to increase people's social capital. The organization has developed a project to assist people in establishing social connections. The project has two major components. One is to assess the effects of increasing social capital and the other to help develop a structure within the community that increases social interactions and involvement. The project will identify existing community resources, link people with special needs to those resources, and encourage active involvement with existing resources in ways that are meaningful to people. Staff training then emphasizes ways to directly assist people to increase social capital and meaningful supports in their respective communities. The assessment component is designed to measure the effects of increased community involvement as a result of participating in the project. The project will help identify strategies that most effectively link people to build social capital while becoming more responsible citizens who can engage in social reciprocity.
- Promote investment of the Qualified Developmental Disability Professional (QDDP) staff in organizational change. The organization has involved the QDDP staff in the Seeing Is Believing initiative, including attending the coalition meetings. Since the QDDP staff are a crucial factor in the implementation and monitoring of organizational transformation at Charles Hines & Son, Inc., their involvement has been critical to their understanding of, and motivation to, support these directions.

- Advocate for consumers. Staff at Charles Hines and Son, Inc. have successfully advocated for and supported people's efforts to live with greater independence in the community. Two recent examples underscore how advocacy made important differences in people's lives. The first person is a young woman who began receiving services while living in her grandmother's home. She felt isolated from peers and expressed a desire to move to a group home where she could meet more young people, have a room of her own, invite friends over, and come and go as she pleased. She moved into a group home housing seven other people in the fall of 2009. A few months later she began to express discontent with the arrangement to her staff and the Qualified Professional who supervised her support services. She felt stifled with the rules of the facility and maintained that she did not feel really involved in the community. She wanted to live in her own home, and began to research how she might do so. She received support to link her to housing options and to resolve financial concerns. In March 2010 she moved into her own home in the community and continues to express delight with her living situation.

  A second example is that of an 18-year-old woman who has received support services through Charles Hines & Son, Inc. throughout most of her childhood. She was one of seven children with special needs who were adopted by a couple, and over the years she has struggled through conflicts with her parents, as she felt that they were overprotective, limited her access to the community, and maintained total control over decision-making. Prior to reaching her 18th birthday,

this young woman began to express a desire to leave her parents' home and to be her own guardian. With support from staff at Charles Hines & Son, Inc., she used AFL supports to move into the home of a family friend in February, became her own guardian, is taking classes at the community college to get her GED, and is determined to complete training to become a massage therapist. She is a very energetic and positive person who will likely be very successful in achieving her goals.

Challenges. First, while the agency has always been conscious about promoting control and choice in support services, there is the reality that when persons with disabilities live with family members, sometimes choice and control of services lies more in the hands of the family and less in the hands of the individual who has a disability. There is the need for continued efforts to raise staff awareness about working on this issue. Second, while for some people, living with their family promotes significant inclusion in the community, for others, this is not the case, and some people with special needs remain very isolated from the community as a whole. With assistance from the CRA consultants, staff are trying to approach families in different ways, and work collaboratively with them to promote greater choice, control, and inclusion for the family member with a disability. Finally, clinical staff regularly encounter challenges in collaborating with case managers who are responsible for developing Person Centered Plans that identify support needs and goals and that ensure all supportive services are person-centered, timely, and include a measure of continuity and stability for consumers and staff. Efforts continue to improve communication between Charles Hines and

Son, Inc. and case management agencies and Local Management Entities so that people receive appropriate supports that enable them to remain in the community.

Beyond Academics

Beyond Academics was initiated by Charles Hines and Son, Inc. in Winston-Salem in 2006. It began with the recognition of a critical need to create more opportunities for youth with disabilities beyond high school. In North Carolina and across the nation, there is a disturbing trend that more than 50% of high school students with intellectual disabilities who graduate have very limited or no community service options for career nor inclusive living arrangements. Charles Hines & Son, Inc. first pioneered a summer program, BASICS, at Winston-Salem State University that introduced students with developmental disabilities to a brief, summer on-campus college experience. The BASICS program was expanded to a year-round program, and Beyond Academics was established at the University of North Carolina-Greensboro. Beyond Academics is finishing a third year at UNC-G, and Charles Hines & Son, Inc. recently spun-off the program to become an independent, nonprofit entity. Currently, there are 25 students in the program. The students take some courses that are specifically for Beyond Academics students, and they also can enroll in general college courses of their choice, with support provided. Some of the steps and strategies that Beyond Academics has used as part of SIB include:

- Increase residential integration. Initially, all of the BA students lived together on campus. They have moved away from this, and now all students have the

opportunity to live in general student or community housing, with housemates of their choice.

- Increase social and leisure connections. They have increased their focus on helping students develop typical campus connections, social relationships, and recreational and leisure experiences.
- Revise strategies to support students in daily living activities. At first, the BA program paid college students as roommates, but then learned that "money does not develop the relationship and may in some ways interfere with it." Also, based on feedback from the BA students, the project is no longer using other students to help teach various daily living skills. The BA students expressed concern that this would negatively affect their relationship with other students as peers.
- Increase connections with other academic departments. The BA program is increasing its connections with other academic departments and programs on campus. Over time, this is helping to increase the inclusive options for their students on campus.
- Learn from other diverse organizations. As an organization that is relatively new and still developing, participation in the SIB has given them an opportunity to learn about successful strategies of other organization, about what to avoid, and about ideas for collaboration with other organizations to help support people across the lifespan.

Challenges. It takes time to develop relationships with university faculty and departments, so that BA students gain access to an increasing array of inclusive educational

opportunities and so that BA students can utilize some of the same support structures that have already been established on campus for other students with disabilities. As the BA staff begin assisting some of their students to think about transition after college, they are concerned about students graduating into a service system that is not as inclusive as their college experience, or receiving more supports than they actually need. Finally, most students do not have Medicaid waiver (CAP) funding and it has been difficult to obtain VR (vocational rehabilitation) funding for the students; staff at BA are looking for diversification in funding streams, including the potential for applying for generic college funding (e.g., Pell grants) to assist their students.

COMMUNITY RESOURCE ALLIANCE: STRATEGIES AND CHALLENGES RELATED TO PROMOTING ORGANIZATIONAL CHANGE

During the first 2 years of the SIB initiative, Community Resource Alliance has utilized a wide range of approaches in order to help promote organizational transformation. Some of the key strategies are highlighted below:

Training and technical assistance to SIB organizations by CRA consultants. CRA consultants have provided extensive training and technical assistance related broadly to person-centered planning, organizational planning, and designing individualized supports to the organizations that are part of this initiative. More specifically, through this training and technical assistance they have assisted organizations to:

- develop organizational plans for change, including building a common vision for change across staff, administrators, and board members

- revise organizational policies and procedures (e.g., staff training, hiring, person-centered planning)
- develop and implement individual person-centered plans, encompassing thinking about people's lives as a whole, across community living, employment, leisure activities, social relationships, and more
- train staff in person-centered planning and in provision of individualized supports that promote self-determination, community inclusion, and social relationships
- assist individuals with disabilities to become involved with self-advocacy
- training for individuals with disabilities and family members about individualized supports, expectations for the planning process, self-advocacy, funding strategies, and other critical issues
- learn about strategies for use of community housing and divestment from facilities, including the issues associated with HUD loans, mortgage options, finance and licensure rules, and the like
- develop true collaboration with other stakeholders in both the public and private sectors to promote changing of rules and regulations that allow both flexible rules and flexible funding to be in place
- develop a "train the trainer "approach which included organization representatives presenting at state and national conferences and consulting with each other and other organizations that have expressed interest

Additional consultants who are involved with an organizational change Community of Practice in Maryland have joined the SIB initiative during the third year of the project.

Technical assistance from other national consultants. The CRA consultants have also, where applicable, linked organizations within the coalition to other individuals and organizations around the country, for purposes of technical assistance and mentorship. For example, national consultants have worked with organizations on the development of microenterprises, strategies to achieve facility closure, strategies to finance and support people to live in generic rather than agency-owned housing, and strategies to assist people to develop community connections and relationships.

Creating a learning community for the agencies involved in the initiative. Attendance at monthly Seeing Is Believing meetings has created a learning community where agency representatives can share successful strategies and support each other in addressing the challenges and barriers. Agency administrators report that taking part in this learning community has been very beneficial, not only in terms of the sharing of successful strategies, but in terms of helping to provide energy and moral support in the difficult task of organizational change. One administrator remarked: "SIB has become a lifeline for us; it has challenged us to think differently, it has given us direction, and has helped us map out where we are and where we want to go." Another administrator commented that, for the QPs who have participated, "this has validated their work, it has energized them, they feel like they are not alone." Finally, an administrator commented that the learning community helps provide "a stronger voice for change than each of us working individually." Several other organizations have joined the SIB learning community and there are an increasing number of other organizations in the state that have indicated they would like to become involved in this initiative, among them several providers of ICFs-MR services.

Reaching a broader audience through trainings and conferences. The SIB coalition has organized some statewide trainings and conferences that have been open to other agencies (in addition to the four directly involved in the initiative) as well as to other stakeholders. One of the one-day training sessions focused on home ownership for individuals with IDD and one large national conference hosted by CRA had over 40 related sessions over three days and more than 280 attendees.

Developing partnerships and collaborations within the state. The SIB coalition has developed partnerships within the state with other groups and initiatives, such as self-advocacy organizations, the NC Emerging Leaders project, and the Money Follows the Person initiative; these partnerships are key to helping facilitate and strengthen the effort to create organizational change and systems change toward increased individualized supports in North Carolina.

Promoting dialog with state agencies regarding individualized supports. The SIB project has engaged in dialog with state agencies, including the Division of Health Services Regulation (licensure), Division of Medical Assistance (state Medicaid authority), and Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, in order to promote collaboration in addressing the barriers to community living in North Carolina. A wide variety approaches were used to promote this dialogue. The focus of the conversations was not "how do we get more money" but rather, "how can we be more flexible in how we support people that will at the same time meet the desired objectives identified by the state?" To the extent that these barriers are addressed, this will facilitate organizational

change, and will help ensure that the opportunity for community living is available to all individuals with disabilities in North Carolina.

CHALLENGES TO THE DEVELOPMENT OF INDIVIDUALIZED SUPPORTS: LESSONS FROM THE EXPERIENCE OF THE SIB COALITION

The work on organizational change by CRA and the SIB Coalition has revealed important lessons related to challenges in developing individualized, person-centered supports. These include:

Organizational change could be greatly enhanced by accompanying systems change. Working on organizational change across a variety of organizations is an effective means identifying common systems barriers. There are a variety of systemic barriers to community living that have been identified during the course of this project. A few of the key barriers include:

- Regulations require licensure of any home with two people who have IDD, if either one has more than minimal support needs.
- Rates and financing do not provide an incentive for providers to develop individualized support services. For example, there is a special assistance subsidy that is available to people who live in group homes but not to many people who live in their own homes, or it is available at a greatly reduced amount.
- Funding reductions and limitations have decreased the flexibility with which the funds could be used, in some cases mandating that people who had lived in their own homes move with one or two others to create small group homes.

- Despite the funding source for smaller settings being Home and Community Based Services waiver on a fee for service basis, the system largely still expects that the same level of staffing/supervision as was present in an ICF-MR will continue in the person's own home despite the lack of funding.
- From the perspective of those who were interviewed for this study, case managers as a whole seem to lack the training and oversight that would assist them in supporting people in individualized ways in the community. Further, the available time that case managers have to support individuals is being reduced on an ongoing basis. With limited time available and many people in crisis, it is difficult to get case managers to identify helping someone move to their own home from a group home as a priority for their time.

There is a need for development of examples of individualized supports, particularly for individuals with the most severe disabilities and intense support needs, in order to help promote further individual and organizational change. When people with disabilities, family members, or agency staff and administrators want to learn more about developing individualized supports, it is important to have specific examples to show them. These must include examples of individualized supports for individuals with multiple and complex support needs. Currently, there are few examples or "success stories" of individualized supports, particularly for those with severe disabilities, and of organizations that have expertise in developing these supports. The development of these examples can be slow and frustrating work, particularly in the face of significant systems barriers that have not yet been addressed. There is still a fairly dominant view that people who have more significant support needs

should be in larger congregate care facilities because it is more cost effective to serve them in these locations. When discussing supporting people who have more substantial challenges in the community in one and two person homes it is not uncommon to hear someone express the belief that "we could serve three people for what that one person costs."

Organizational change is not just about facility closure; it must first focus on building and strengthening the culture and foundation of organizations. "Success," particularly in the early stages of organizational change, is not only about helping people move out of facilities, but also, equally importantly, about building a strong foundation of organizational capacity to assist people to move out of facility-based services, avoid placement in facility-based services, and experience inclusion. This has been equated with "turning a battleship in a bathtub." Without this foundation, some organizations have found that they have made the mistake of assisting individuals to live in community settings, but without a well-established network of support and without a shift in power and control and with increased loneliness for the individual who moved. Absent these organizational significant shifts, any gains tend to be very temporary.

Organizational change and building a strong foundation for community supports is complex, multi-faceted, and requires ongoing, long-term, steady effort, even among the most progressive agencies. This is particularly the case with organizations that have a strong history and culture of facility-based services, as well as those organizations that exist within systems that have deeply entrenched institutional orientations. In situations like this not only do practices need to be changed, the organizational culture, and the associated values, must change as well. It is necessary to find the organic tipping point for the change to be sustained

over time. When organizational change happens too quickly without the creation of a strong foundation, there is a risk that the community supports will be created that are not truly individualized, that do not include adequate organizational and community support, and that do not offer increased control and choice to the individual. For example, in too many organizational change situations the person-centered plan becomes little more than a perfunctory meeting with a few professionals to fill out a form that supported and justified existing programs and services with little true effort to customize the support. At the same time, if change is too slow to occur, individuals with disabilities spend needless time in segregated facilities.

A 3-year project limit will significantly curtail the opportunities for creating sustainable organizational and, potentially, systemic change. Many state DD Councils traditionally fund projects on a relatively short-term basis (e.g., up to 3 years). This model has the potential to work well for small pilot demonstration grants. However, in order to achieve foundational, systemic change and tangible outcomes that apply across multiple environments, it is necessary to review how organizations and systems engage in the change process and to realize that in the vast majority of cases 3 years is not sufficient to establish a firm foundation for long-term systems change, especially when the organizations are struggling to make change against a regulatory and funding basis that is strongly oriented toward traditional services. After 3 years some initial organizational changes have occurred and key systems issues have been identified and are beginning to be addressed through this coalition. A longer-term funding cycle (e.g., perhaps 5 years) would be more conducive to laying the foundation for long term sustainable outcomes.

CONCLUSIONS

In spite of the frustrations and challenges associated with this type of work, there have been many accomplishments associated with the SIB initiative. In summary:

- organizations have increased their capacity to plan and develop individualized supports
- organizations have begun to make foundational changes in culture, policy, and procedures that will support and enhance the development of individualized supports
- organizations have begun to develop the capacity to think in new and different ways about housing, employment, and community relationships and participation for people and to design strategies and initiatives based on this
- through multiple cross-system collaborations, a forum has been created for organizations to work together on organizational change, with the assistance of state and national consultants; this collective work has created significant positive energy and commitment among the participating organizations and has attracted the interest of additional organizations in the state, which helps to assure that it will become a new expectation for how services are delivered and that it will also become self-sustaining
- critical systems issues have been identified and dialogue has begun with state agencies in order to try to address barriers

- at the time of this writing SIB participating agencies have assisted approximately 35 people to move from a wide variety of settings, including ICFs-MR and other group homes, to their own homes and apartments

At the same time, there is much more work to be done, including:

- continuing to assist organizations to develop individualized supports, so that increasing numbers of individuals, including those with severe and complex support needs, have this option, and so that others can see and learn from these examples
- expanding the capacity of organizations to develop individualized supports and make accompanying organizational changes, such as in staff training and staff roles, funding, and other organizational policies and procedures
- working in collaboration with state-level entities to figure out how state values, policies, regulations, and funding structures can be aligned to support and give incentive to organizational change toward supported living for all and to address the current barriers
- working to expand access to self-advocacy
- working in closer collaboration with families and guardians, so they feel secure with and invested in the effort to increase the opportunities for supported living
- development of materials (e.g., New York State Association of Community and Residential Agencies, 2009) that assist families and individuals with disabilities to learn about supported living and to learn about the process required to obtain supported living

- working to ensure that case managers and others working in other parts of the system receive training and monitoring that supports individualized supports, so they truly understanding, have opportunities to be part of and learn person-centered planning approaches, etc.

The North Carolina Council on Developmental Disabilities' investment in this organizational change initiative is a model for other states. Increasingly, across the country, individuals with disabilities and family members are expressing the desire for an alternative to traditional facility-based services, and states are eager to espouse the values of individualized, person-centered supports and community inclusion. At the same time, cultural, structural, and regulatory shifts need to be made, at both the organizational and systems level, in order to most effectively offer genuine individualized, person-centered supports.

Work to date by CRA and the participating organizations has begun to lay a critical foundation for individual change, change within organizations, and for dialog and partnership among different stakeholders. A steadily growing number of organizations throughout the state are attracted to the work that is being accomplished through the coalition. The addition of partnerships with new consultants and other organizations around the country that have experience and expertise related to organizational and systems change will enhance the SIB project as it moves forward. Continued efforts in this direction will help to ensure that individuals with disabilities and their families can both see and believe that individualized, person-centered supports are a real option for all individuals with developmental disabilities in North Carolina.

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