RESOURCES ON ORGANIZATIONAL CHANGE: FROM GROUP HOMES AND OTHER FACILITY-BASED SERVICES TO INDIVIDUALIZED SUPPORTS

An Information Package from the Center on Human Policy

By
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PART I

ORGANIZATIONS WITH EXPERIENCE IN
CONVERSION FROM GROUP HOMES TO
INDIVIDUALIZED SUPPORTS

The purpose of this section of this information package is to share information about organizations that have experience with group home closure and movement away from facility-based services. It is not intended to provide an exhaustive list of organizations that have closed group homes. However, it is meant to provide information about a variety of organizations of differing sizes that have taken varying approaches to group home closure and the transformation to provision of individualized supports. Some of these organizations have closed all of their group homes, and some still have group homes remaining. Some have closed group homes rapidly, while others have closed them over the long term. All of the organizations have invested major effort in shifting their services and organizational culture toward person-centered, individualized supports.
**Onondaga Community Living**  
http://www.oclinc.org/  

Since 1990, Onondaga Community Living has been transitioning away from group homes. They originally had three 6-person group homes. Two of those group homes have closed, and the third has three people living there. Individualized person-centered planning processes have been used to assist people to move from the group homes to settings of their choices. Additionally, all people who are new to the agency are supported with individualized supports.

**Total Living Concept**  
http://www.totallivingconcept.org/  

Originally, TLC had three group homes with eight people each. In the 1980s, they began investigating the possibility of assisting people to move out of the group homes into their own homes. By the early 1990s, TLC closed its group homes and assisted everyone to move to a house or apartment. Currently, the organization supports 30 individuals to live lives of their own in homes of their own.

**Jay Nolan Community Services**  
http://www.jaynolan.org/  

Jay Nolan Community Services was established in 1975, and initially supported people with autism and other disabilities in group settings. In 1992, JNCS changed its philosophy and the way it was delivering services. They closed their group homes and began providing individualized support to enable people to live in their own homes, have jobs, and participate in other valued community activities.
Hope House Foundation
http://www.hope-house.org/

Hope House Foundation was established in 1964, and initially opened 13 group homes. In the 1980s, they began closing their group homes, and supporting people in their own homes in the community. Today the organization supports approximately 130 people with individualized support services.

Arc of Rensselaer County
http://www.rensselaerarc.org/

The Arc of Rensselaer County supports approximately 160 people. Of these, 60% live in individualized community settings. They closed a 10-person group home, and have assisted 20 other individuals to move from group homes to their own homes. They have shifted their organizational culture so that the orientation now is toward individualized supports rather than facilities.

Nonotuck Resource Associates, Inc.
http://www.nonotuck.com/

Nonotuck Resource Associates, Inc. has been providing residential services to people with developmental disabilities in western Massachusetts for more than 25 years. The organization closed 15 group homes and assisted the 54 individuals to move into 50 distinct and personalized living arrangements. Each person now lives in a home of their choice, with people of their choice.

CLS, Inc.
http://www.comliveserv.com/

CLS, Inc. supports approximately 2,000 individuals in the Detroit metropolitan area. In the past 15 years, the organization has undertaken significant
transformation away from group homes toward individualized, self-directed supports and self-determination. By the early 1990s, they had over 250 group homes operated by 60 providers, including 76 6-person ICF/MRs. Since 1995, the number of individuals in licensed group homes has decreased from over 1,200 to about 700; at the same time, the number of individuals in their own homes has increased from 300 to almost 1,200. The organization expanded into Oakland County, offering only self-determination services.
PART II
REFERENCES: ORGANIZATIONAL CHANGE TOWARD SUPPORTED LIVING AND THE DEVELOPMENT OF INDIVIDUALIZED SUPPORTS

The resources listed here relate broadly to organizational change and the development of individualized, person-centered supports. They include resources on issues related to conversion from group homes to individualized supports; leadership for change; person-centered planning; and the development of individualized supports.


Lyle O’Brien, C., O’Brien, J., & Mount, B. (1997). Person-centered planning has arrived...or has it? *Mental Retardation, 35*, 480-484.


PART III
SELECTED CASE STUDIES AND ARTICLES RELATED TO ORGANIZATIONAL TRANSFORMATION

Case Studies
2. Onondaga Community Living: A Story of How an Agency Changed One Person at a Time by Patricia Fratangelo, Bob Ciota, and Michael Kendrick
3. Facility Conversion and Beyond at the Arc Northern Chesapeake Region: A Story of Visionary Leadership and Strategic Planning (2010) by Pam Walker
4. How I Worked Myself Out of a Group Home by Brad Jones, Helen Cobb Jones, and Don Shouse

Informational Articles
2. A Place of Our Own by Lyle T. Romer, Mary A. Romer, Darla Emerson, and Brad Jones.
Getting a Life in Wayne and Oakland Counties, Michigan: Using Self-Determination as a Foundation for Organizational Change

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

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Many want to label and categorize Self-Determination as a program, a home, or a budget... It is about “getting a life.” It is about living in houses and homes, not residential settings or sites (Dehem, Kovach, & Devon, 2005, p. 29).

INTRODUCTION

Community Living Services (CLS) is a large nonprofit corporation that promotes “community inclusion, full citizenship, and a self-determined life” for people of all ages with developmental disabilities. The organization has undertaken significant transformation in the past 15 years. This report focuses on that transformation, particularly with respect to community living services.¹ It is based on a site visit to CLS, Inc. in May 2009, which included interviews with administrators of CLS and contracted service providers, direct support staff, individuals with disabilities, and family members, as well as review of documents.

BACKGROUND

The state of Michigan originally formed Community Living Services (then called Wayne Community Living Services) in Wayne County (which encompasses Detroit and part of the outlying metropolitan areas) in 1984 as part of its efforts to close three institutions in Wayne County. The operation of CLS was transferred to the Detroit-Wayne County Community Mental Health Agency (D-WCCMHA) in April 1992 as part of a planned transfer of

¹This report is part of a series of case studies on organizational transformation from traditional facility-based services to individualized supports.
responsibilities from the state to local community mental health control. CLS incorporated as a nonprofit agency and contracted with D-WCCMHA to continue its programs. At the onset, through diligent negotiations and a dedication to systems change, CLS formed its Board of Directors for leadership that would represent the people it supports. The board is made up of people from advocacy organizations, people supported by CLS, and family members of people supported by CLS who also come from business (finance, legal, and human resource) backgrounds. These leaders have the personal and professional qualifications, as well as the dedication, to successfully navigate CLS through its transformation. The CLS Board Treasurer said it best, “As a banker and a brother of a person with a developmental disability, I have to make sound financial decisions that are balanced with what is best for business and what is best for the people we support” (Saules, 2009).

CLS is contracted by the Detroit-Wayne County Community Mental Health Agency to be both a Manager of a Comprehensive Provider Network and a Support Service Provider. It assists people in developing a person-centered plan and creating an individual budget. The organization provides support coordination services (as well as other services, such as skill-building, behavioral health supports, respite, supported employment, gentle teaching) to assist people to obtain the supports and resources, formal and informal, that they need for inclusive community living. Finally, the organization contracts with a network of providers for community living supports and services.

At the outset, the organization developed many group homes, particularly 6-bed Intermediate Care Facilities for the Mentally Retarded (ICF/MRs). By the early 1990s, they had over 250 group homes operated by 60 providers, including 76 6-person ICF/MRs. Many
people spent their days in large segregated day programs, some serving 150 people, through contracted providers. The agency employed over 120 clinical staff. Support coordinators spent much of their time on paperwork. In summary, in their own words, “The organization was Medicaid-driven and clinician-driven; there was no person-centered planning nor much choice; we moved people like chess pieces” (Dehem, n.d.).

Since the mid-1990s, there has been significant organizational transformation at CLS, Inc. from a service model to a support model, based on the principles of self-determination. According to the director, at that point in time, they were proud of their accomplishments; they were serving a large number of people, and had helped many of them leave institutions. However, some of the people they supported began to be dissatisfied with the group home model of service: “People wanted fewer housemates. They wanted freedom from the structure of a group home and, in particular, from the controlled rigidity of life in an ICF/MR home....The focus became a clinical treatment milieu rather than what people and those close to them wanted in life” (Dehem & Chapman, 1997, p. 10). At the same time, agency and state administrators were learning about self-determination, and about innovative, individualized supports that were being developed in other places. Michigan was one of 19 states that applied for and received a self-determination grant from the Robert Wood Johnson Foundation from 1997-2000; WCLS was one of the pilot project sites in Michigan. This gave it the opportunity to begin implementing self-determination on an individual and organization-wide basis. This served as the springboard for organizational transformation that has continued to occur since that time.
CLS Wayne County has 3,000 people enrolled in services; 1,000 people live at home and receive only supports coordination services; 1,900 people have an individual budget and receive additional supportive services. Of the 1,900, 700 have self-determination services and their individual budget payments flow through a fiscal intermediary. CLS Oakland County supports 600 people, all of whom receive services and have an individual budget paid through a fiscal intermediary agency. The individual has the option to contract directly with a staffing agency (73% in CLS Wayne County and 65% in CLS Oakland) and share the management duties of the direct care staff, or they direct hire their own staff (27% in CLS Wayne County and 35% in CLS Oakland), meaning they are the employer of record and fully manage their direct care staff. These individuals live in their own homes, rather than contracting with providers to operate licensed group homes. Since 1995, the number of individuals in licensed group homes has decreased from over 1,200 to about 700; at the same time, the number of individuals in their own homes has increased from 300+ to almost 1,200. Additionally, CLS has expanded its ability to offer self-directed support by expanding into Oakland County and Kentucky, as well as by expanding into services for homeless people and elderly people. In an effort to share what it has learned and help others to learn about self-determination based support models, CLS has established the Center for Self-Determination, a national training, consulting, and technical resource center designed to help advance self-determination based support models nationally.

**STATE CONTEXT**

Change at CLS has occurred within the context of significant change in the state, particularly in relation to community living, self-determination, and managed care.
Community living and self-determination. The state of Michigan has long been a national leader in the development of supports that promote inclusive community living and self-determination. In the 1980s, the state focused on supporting children to live with families, rather than in institutions or group homes (Taylor, 1991). In 1995, the State of Michigan, through an effort initiated and led by advocacy groups and later partnered with the Arc of Michigan, UCP Michigan, and Autism Society of Michigan, lobbied to replace, in state statute, the term “Mental Retardation and Related Disabilities” with “Developmental Disabilities.” These efforts broadened the definition, which then supported the development of a unique 1915(b) Medicaid waiver. This waiver eliminated waiting lists for people who met the definition of having a developmental disability and allowed a person who met the institutional level of care the option of supports in the community (Hoyle, 2009). Since that time, the state has become a national leader in supporting people with developmental disabilities and moved in the direction of supporting all people (children and adults) to live in the community rather than institutions, through the close of its state institution. At one time, there were 13 institutions, and only 1 now remains, which is scheduled for closure in 2009. In a national analysis, Michigan was ranked 6th, overall, in its use of Medicaid services in a manner that helps to create a “quality, meaningful and community inclusive life” (Bragdon, 2009, p. 3).

As noted previously, from 1997-2000, the state had a grant from the Robert Wood Johnson Foundation for a self-determination pilot project, which included Wayne Community Living Services. As part of this project, there were statewide self-determination trainings,
leadership forums, and conferences. Since 2000, self-determination and the option for self-direction of services is part of state policy.

**Managed care.** Since 2002, in Wayne County, Michigan, through the Detroit-Wayne County Community Mental Health Agency, all developmental disability, mental health, and substance abuse services were transitioned to the managed care system, a pre-paid, capitated system. The Detroit-Wayne County Community Mental Health Agency, with whom CLS contracts, was also required to introduce competition at the service level and developed a system of six competitively bid Managers of Comprehensive Provider Networks (MCPNs); CLS was selected to be one of the 3 MCPNs for people with developmental disabilities. Individuals choose their managed care network. Everyone who enrolls or switches from another MCPN must be served as there are no waiting lists in Michigan for people receiving Medicaid funded services. Each person selects a Manager of a Comprehensive Provider Network (MCPN), gets assigned a rate based upon prior funding and encounter data for each person, and then a per member per month fee is paid to the MCPN. The total amount of funding available for the month is adjusted by the county among case rate levels so as to balance across eligible active members.

**ORGANIZATIONAL CHANGE AT CLS**

**Strategies for Change**

Following the RWJ self-determination project, Michigan adopted a statewide policy of self-determination. In Wayne County, following the project, there has been ongoing effort to transform the organization based on the principles of self-determination, and make the option of self-determination available to all people. The organizational transformation has
entailed a multipronged approach. Key components and strategies of this process are highlighted below (described in more detail in Dehem, 2008; Dehem, & Chapman, 1997; Dehem, Kovach, & Devon, 2005; Taverna, 2009). As noted earlier, the focus of this study was community living, so more emphasis is placed on information related to this area.

Creating a new mission and vision as the centerpiece of change. CLS has used the concept of self-determination as a foundation for its organizational transformation. The principles of self-determination include: Freedom: to decide how one wants to live their life; Authority: over a targeted amount of dollars; Support: to organize resources in ways that are life enhancing and meaningful to the individual; Responsibility: for the wise use of public dollars and the recognition of the contribution individuals with disabilities can make in their communities; Confirmation: of the important role that self-advocates must play in a newly redesigned system (Nerney & Shumway, 1996). Based on these principles, the vision of CLS is: People will fully participate in their communities and have a quality of life which comes from freedom and its responsibilities, the authority to make their own life decisions, and the control of resources to implement them. The mission of CLS is: To assist and advocate for each person; To control and exercise authority over their own lives; To live a life of freedom, opportunity and relationships, as family, friend and neighbors; To share in full community membership and citizenship. It has been critical not only to articulate this vision and mission, but to keep them visible to all who are involved with CLS in any way, through trainings, conferences, in organizational materials, and so forth.

Providing education, training, and technical assistance. As a first step, agency leadership had to relearn how and what to lead. Then, they had to provide education,
training, and technical assistance to agency staff and the staff of contracted provider agencies. They spent a lot of time and resources doing training by bringing in experts, to help build the capacity of the staff and organization as a whole to provide supports that aligned with the new mission and vision (e.g., person-centered planning, individualized supports, gentle teaching, building community connections and relationships, organizational implementation of individual budgets and consumer control, etc.). Originally, most of the training resources were focused on staff, but in recent years, more training is directed toward individuals and families, assisting them to learn about self-determination and self-direction. Additionally, the organization uses many individuals with disabilities and families to help provide training. Finally, the organization has offered training to community organizations, such as schools and police officers, to raise awareness about the role they can play in supporting community inclusion.

**Changing operations and finance systems to align with self-determination.** There were a number of components to this aspect of transformation (Dehem, 2008; Taverna, 2009). These included:

- The development of person-centered planning and individual budget processes, as well as “unbundling” service expenses and tying them to an automated database that incorporates a written, authorized process.
- The development of specialized financial positions with skills in money management, negotiation, and meeting facilitating. These specialized positions were developed through restructuring and shifting existing personnel resources.
• The development of protocols that ensured continual communication between individuals/families, personal agents, operations directors, and other stakeholders with financial analysts.

• The preparation of training modules and materials that are user friendly to the person and family members. These included materials to educate people about self-determination. People with disabilities were involved in helping develop these materials.

**Shifting from residential services to residential supports.** This involves shifting away from provider operated group homes to assisting people to live in homes they own or rent, with housemates of their choice, and support staff of their choice. In the case of CLS, it is not a provider of residential supports, but contracts with providers for this. So, the shift away from provider-operated group homes necessitated much education, training, technical assistance, and financial incentive to contracted providers. Some of the key components of this included:

• Offering education, training, and technical assistance for providers. The first aspect of this was education about the new mission and vision that was being implemented. Accompanying this, there was significant opportunity for education, training, and technical assistance related to implementing this mission and vision (e.g., as noted above). CLS invited providers to submit proposals for assistance to transition people out of group homes. CLS provided help with cost shifting, with shifting from licensed group homes to people’s own homes, where they sign the lease, and with meeting the costs associated with transformation. CLS encouraged providers to gain
experience in offering individualized supports by working with people they already knew, and by “starting small,” and working with a few people at a time, rather than trying to help everyone at once.

- Forming a “blue ribbon” committee of providers. Prior to the organizational transformation, some of the providers in the county had already been making efforts to support people in self-determination, within the context of a system that was not entirely conducive to this. As CLS began its transformation, they invited these providers to be part of a work group to share strategies and help promote further self-determination. Over time, particularly as other providers realized that this was the direction that CLS was headed, they were interested in joining this group. Over time, this group has served as a platform to build trust and understanding about the mission and changing direction of CLS; the meetings have been vital to “turning the corner” on the skepticism and fears associated with self-direction (Dehem, Kovach, & Devon, 2005).

- Establishing incentives to reward effort and excellence. In 2007, CLS implemented a policy of not paying for vacancies in group homes; group home providers now absorb some of these former costs. CLS does pay for all vacancies in self-directed situations. A premium staff rate is applied to budgets that involve self-determination: Provider reimbursement in Michigan is $12 per hour, but CLS paying $13 an hour when people live in their own home. They are able to direct these additional resources toward self-determination, since it saves the maintenance expense of a group home.
Transitioning from vocational service contracts to community employment. CLS has transitioned from vocational service contracts to community employment and skill building contracts, with a rate structure that pays its contractors higher rates for providing these services. They have assisted a number of people to develop microenterprises. They choose to limit access to workshops, and are working with like-minded providers to reduce and eliminate segregated employment. At the same time, they are directing resources to helping people find employment in the community through an employment incentive project or “finders fee,” a one-time payment for assisting an individual with a developmental disability to secure community employment.

Moving away from agency-based clinical services. In the past, CLS had approximately 128 clinicians (nurses, psychologists, etc.) on their payroll. However, it wanted to move away from a medical-based, clinician based model of services. According to the director, “there were clinicians on everyone’s team, and we were always talking about diagnostic issues and treatment goals; it seemed that the service was the outcome, rather than people getting a life. Also, there was very little accountability for whether their services were effective.” CLS had an opportunity to have an out of state company come in and offer employment to the clinicians. Now, it contracts for clinical services, and the clinicians provide services that the individual desires and needs as decided upon by the individual and their circle of support. Clinicians no longer direct the planning process; it is directed by the individual and their circle of support. It has worked to create a balance, wherein the clinicians are not necessarily altogether out of people’s lives, but where they do not play a dominant role. The clinicians do not automatically come to planning meetings, or CLS staff may arrange separate meetings to
address the clinical issues. In addition, protocols were developed for all stakeholders, accompanied by training on the protocols, to assist in reducing unnecessary or duplicative clinical services. Clinical savings have been in excess of $1 million per year.

Reducing guardianships. To administrators at CLS, it seemed that guardianship and self-determination are antithetical (Newman, 2009). The chairperson of its Board has been a national leader in alternatives to guardianship, so he helped spur the organization to focus some energy in this direction. CLS supports people in moving away from traditional guardianship situations to having friends or relatives with Powers of Attorney or having no legal representative at all. Through informed consent board meetings with independent advocates, it has assisted several hundred people, who now have just powers of attorney, or have had guardianship entirely eliminated. The agency has also provided training and education about alternatives to guardianship to all stakeholders, including local judges.

Changing roles of staff. In particular, it was critical to change the roles of the service coordinators and supervisors. Previously, people in these positions spent a lot of time doing paperwork. Now, the service coordinators are “personal agents,” and focus on helping people connect to formal and informal supports, relationships, and so forth. Supervisors are Coaches, who focus on training and mentoring in the person-centered planning and individual budgeting.

Revising the Quality of Life standards. CLS has revised their quality of life standards based on the guide, “Real Life Quality Standards,” produced by the Center for Self-Determination (Nerney, 2005). The “Real Life Quality Standards” focus on five typical human aspirations: health and safety, a place of one’s own, community membership, long-term
relationships, the production of income, and control of transportation. These quality standards are used as part of the person-centered planning process at CLS.

**Diversification of the funding base.** CLS has developed subsidiary companies to support its mission and values. These include Liberty Hill Housing Corporation, a nonprofit company providing low-income housing options to people supported through CLS and The Center for Self-Determination, a nonprofit training and resource company supported self-determination initiatives. CLS branched out to another state by contracting with Kentucky to transition people with developmental disabilities out of institutions and into the community and offer self-determination services to people with developmental disabilities living in their own homes. More recently, CLS branched out through new contracts to other areas such as services for seniors and for people who are homeless.

**Markers of Change**

CLS, Inc. has chosen to track certain data as partial indicators of change toward assisting people with community inclusion, full citizenship, and a self-determined life. For example, the number of people with self-directed budgets began at zero in 1997 and was at more than 600 in 2008. As previously noted, since 1995, the number of people in licensed homes has decreased from 1,200 to 700; at the same time, the number of people living in their own homes has increased from 400 to more than 1,100. People who had powers of attorney versus guardianships increased from 53.7 (per 1,000 people) in 2004 to 154 in 2007. The average person per household has decreased from 2.8 in 2001 to 2.22 in 2008. Data from two provider organizations in Wayne County reveal that the rate of staff retention is much higher with self-determination; staff turnover was 87% in group homes, as compared to the
teens or less when people hire their own staff. Other data indicate an overall lower rate of recipient rights and fire safety incidents with self-determination, and that, overall, self-determination costs are lower than traditional services. Finally, satisfaction surveys reveal a 95% or higher satisfaction rate for people who are supported by CLS.

At CLS, there is recognition that these data are only partial indicators of the extent to which the organization, and people’s lives, have changed. For example, self-determination is about more than just helping people move from licensed to unlicensed settings, or to settings with fewer housemates. It is primarily the stories of transformation in people’s lives, a transformation that cannot be quantified or measured, that are the ultimate markers of organizational change. The following are two examples:

Laurie.² When she was 18, Laurie moved out of her parents’ home and lived in a series of relatives’ homes and foster homes. In between places, she sometimes lived on the streets and drank heavily. Laurie then moved into a home with another woman with a disability, with staff hired through a provider agency. However, she had difficulty with the rules and structure. A CLS staff member, Bill, who specializes in Gentle Teaching had been working with Laurie, and he offered to help her make a change in her living situation. Laurie and Karen had become acquaintances through seeing each other around the neighborhood. Karen, who rents a house, was looking for a housemate to share the rent. Bill, as well as Laurie’s support coordinator, Terri, assisted Laurie to work out arrangements with Karen. Laurie has shared a house with Karen since October 2006. In addition, Laurie hires Karen as a live-in companion. When Laurie first moved in, Karen struggled a little to figure out how best to support Laurie,

²All names in these accounts are pseudonyms.
who in addition to having a mild intellectual disability also has a mental health label of “reactive/affective disorder.” Karen said that the “gentle teaching” support provided by Bill to both Laurie and herself has helped them get through the difficulties, such as when Laurie becomes depressed or anxious. In addition to the “gentle teaching” support, Laurie regularly sees a psychologist; however, in the past year, she has decreased her usage of this. She also has a support coordinator at CLS who helps with annual planning, and implementation of that plan. They meet together approximately nine times per year. For one thing, Laurie would like another job. Right now, she works at McDonalds two days a week, and does some pet sitting for neighbors. Overall, the ability to hire Karen, someone whom she knows and trusts, is key to the success of this arrangement for Laurie. While Karen provides support and guidance, it is within the context of a positive, caring relationship.

Harry and Eleanor. Harry and Eleanor met and became friends when they were both in Plymouth Regional Center. After leaving Plymouth, they both moved around a lot, and lost touch for awhile. Harry lived in another regional center, a group home, and then a couple of supported living situations with roommates. Eleanor also moved around from a group home to a supported apartment. Harry asked CLS for Eleanor’s number, and they were able to begin spending time together again. They got married 11 years ago. Harry explained that his brother was best man at his wedding: “I told him, I was best man at your wedding, so now it’s your turn to be my best man.” At first, after getting married, they could not move in together, since they were being supported by different residential service providers. Staff at CLS told them about self-determination, which was just beginning as a pilot project in Michigan. They switched to a provider agency that was involved with the self-determination initiative. Harry
and Eleanor’s support coordinator assisted them in selecting the apartment. The provider agency gave them names of potential support staff, and assisted them in conducting interviews and hiring the staff. Currently, they have one staff person who works from 8:00a.m.-4:00p.m., and another who works from 4:00p.m.-9:00p.m. They do not need staff overnight. Additionally, they have a personal agent, Joe, who they see approximately every 2 weeks, who helps them with annual planning, as well as implementing the plan. Both Harry and Eleanor used to work in sheltered workshops, and both do not want to spend time in one again. Joe has assisted Harry to start his own arts and crafts business; he sells them at various community events and gatherings. Eleanor spends her days doing a variety of things, including learning to use the computer, swimming, self-advocacy work, and household errands and chores.

There are many aspects of life that Harry and Eleanor feel are different and better with self-determination. They appreciate being able to interview and hire their own staff. In the past, neither of them had much choice about housemates or staff. With their van, and staff assistance in driving, they are able to make their own plans about daily and weekly activities: “We go where we want to, when we want to.” They are also able to hold onto their own money, and make decisions about how to spend it. Harry has family members who live nearby. He did not used to be as comfortable inviting them over to visit when he lived in a group home, as he used to feel that even during these visits “like someone was watching over my shoulder.” Now, both he and Eleanor enjoy having family or friends over. Harry and Eleanor are both very involved in self-advocacy, so that other individuals with disabilities can have same opportunity that they do self-determination.
Additional Initiatives

Since 2000, CLS has developed a number of new initiatives as a means of promoting self-determination. The agency has expanded its services into Oakland County, Michigan, and, on a much smaller scale, into Louisville, Kentucky. Additionally, in Wayne County and Oakland counties, CLS is serving homeless people and elderly people, with services that incorporate self-determination. Finally, as noted earlier, CLS is host to the Center for Self-Determination. Each of these initiatives is described briefly below.

CLS/Oakland County

Oakland County, a large county north of Detroit, historically had only one choice of agency that served people with developmental disabilities, primarily through group homes. CLS/Oakland is supported by the Oakland County Community Mental Health Authority as a core provider. The Authority wanted more than the one core provider they had at the time serving individuals with developmental disabilities and further wanted one that exclusively was designed to support people using a self-determination philosophy and the tools of individual budgets, fiscal intermediaries, and independent support coordinators. The Authority chose CLS through an RFP process. Initially, until the program was up and running and office space was established, administrators of CLS/Oakland County, who had been long-term employees at CLS/Wayne County, worked from their offices in Wayne County.

From the outset, they were clear that they were not going to establish group homes. They also do not promote sheltered work, although some people who receive their supports are in sheltered work programs. This actually creates an opportunity for them to introduce people to the possibility of individualized employment and day supports. As the director put
it, “You’ve got to have a way to introduce people to another way.” Often, as CLS presents new possibilities and opportunities (e.g., microenterprises, college classes, volunteer work, etc.), people start scaling back on sheltered work either partially or entirely.

One of the unique aspects of CLS/Oakland County is independent support coordination; that is, support coordination provided by people who are not employees of CLS, Inc. In Wayne County, the support brokers are employees of CLS, although they are working on establishing some independent support coordinators. The independent support coordination was easier to establish in Oakland County, as the organization was new and thus did not have a pre-existing structure of embedded support coordination. Family members can be hired as support coordinators, but guardians may not be hired. Some support coordinators work with only one or a few people; the maximum number of people they can work with is 20.

Funding for community living and day services is combined. This increases flexibility, avoiding a separation between day and residential services. In addition, as an administrator noted, “It helps, with the combined funding, because staff are not in a position to say, ‘That’s not my role.’”

Growth in the organization has been rapid; they support almost 600 people. When people first come into the organization, support coordinators assist them in creating an initial plan and a budget. About one-third direct hire their staff, and the other two-thirds use a staffing agent. They use some of the Wayne County agencies who are familiar with self-determination, as well as some new ones that have been developed. According to an administrator, “Some organizations have embraced this; others still need education.”
Overall, according to an administrator, “Satisfaction is very high, and people hear from other by word of mouth and transfer to CLS/Oakland.” Again, their satisfaction is best illustrated through their stories, as demonstrated in the following examples:

**Eddie.** Eddie, who is 24 years old, was born with cerebral palsy. When he was young, his family moved around a lot due to his mother’s work. Thus, he had to change schools frequently, and had a difficult time meeting people and making friends. They were living in Baltimore when he finished high school. After that, his mother wanted him to move into a group home. Instead, Eddie moved back to Michigan and lived with his grandmother for six months. Then, he contacted a community housing organization in order to find a housemate; this organization referred him to CLS. Then, as Eddie put it, “I contacted CLS and learned about self-determination and my life hasn’t been the same since. It changed my whole life around.”

In 2004, Eddie began working with a support coordinator from CLS. His first priorities were finding a place to live, a housemate, and support staff. Over the last five years, he has tried out a variety of living situations and housemates. For awhile, he hired a live-in staff person. That arrangement did not work well, so Eddie found another housemate, a man who also uses support services. With assistance from his support coordinator, Eddie hires his own staff, using a fiscal intermediary to help pay them.

Eddie’s support coordinator, Sharon, has also worked with him to establish his own business. He is a disc jockey, specializing in salsa. Sharon helped him organize a fundraiser in order to purchase equipment for his business. Eddie has a friend who is a DJ who has taught him how to use some of the equipment; in addition, Eddie has taught himself how to use
much of the equipment. Sharon has helped him with a number of other things, including finding other paid work, applying for and maintaining benefits, enrolling in community classes, and meeting other people. For a time, Eddie worked as a peer housing specialist on a grant-funded project. He has also begun doing public speaking about self-advocacy and self-determination, including some out-of-state travel to conferences. He took a public speaking course in order to increase his speaking skills and confidence. He is on the Oakland County Mental Health Consumer Advisory Committee and on the Oakland County/CLS Citizens Advisory Committee. In 2009, Eddie was honored statewide as Youth Advocate of the Year. Eventually, he would like to study music at the college level and get his driver’s license.

Jacob. Jacob, who is 26 years old and has Down Syndrome, moved into an apartment with his friend Kevin in September 2008. Since he was in high school, he has consistently talked about his desire to move out of his parents’ house, as his older brothers had done before him. The last few years that he lived at home, Jacob’s parents began preparing him for this move by creating for him his own apartment space within their house. Jacob’s parents and his support coordinator, Patti, assisted with all the preparations for the move, including selecting an apartment, and hiring support staff. Jacob and Kevin were friends, and decided they would like to be roommates. They share 56 hours of staff support per week; in addition, Lisa provides Jacob with an additional 7 hours of support per week. Jacob and Kevin use a staffing agency, who introduces them to potential staff, that they then interview and select from.

Jacob attends Oakland University’s transition program, an inclusive program through the Rochester community schools, on the Oakland University campus. At OU, he also swims
with the Masters Swim program. It is through OU that he met his housemate; also, at OU, he met Lisa, who was volunteering with the program there, and then began providing support to Jacob, when he was still living with his parents. When Jacob graduates from OU, he will hire Lisa to provide additional hours of assistance to him with work and other pursuits.

Currently, Jacob is exploring a lot of interests, some of which may turn into paid work. Like Eddie, Jacob loves music, and has been learning about being a DJ; Eddie has been serving as a mentor, assisting him to learn about the equipment and other skills. Patti is helping him create a website and do the paperwork required to establish a DJ. As part of this, Jacob took a course offered by CLS on microenterprises, and is receiving assistance from CLS to form a business plan. He currently is gaining experience as a DJ by hosting an on-air show every Friday morning at Oakland University’s radio station. Also, he took a course at Community Media Network, a media public access organization. After the course, Jacob and a friend expressed interest in continuing their involvement at Community Media Network. So, now, the two of them co-host a TV show, “Community Corner.” Each show they interview guests about community resources and issues that affect the lives of people with disabilities. He has taken public speaking courses, as well as video production and editing classes. Recently, he applied for a position doing training in self-determination and self-advocacy for others with disabilities and staff at a local university. Finally, Jacob volunteers at the Michigan Humane Society and the Rochester Hills Public Library.

Jacob’s parents feel that the move has worked out well, and they feel that Jacob is very content with his move and his current living arrangement. They observe that, “Lots of parents think it’s their responsibility to keep their children forever; in that mode, you don’t
get much willingness to try other things.” For them, while as parents they always keep a watchful eye on Jacob, the key to this move and all else that Jacob is involved in is their openness to letting him try out new experiences and pursue opportunities as they arise.

Kentucky

CLS has been a provider in Louisville, KY, as a contractor with the Commonwealth of Kentucky, since 2007. The purpose of this initiative is to reduce the number of people in facility-based services. Currently, 25 people are supported by CLS/Kentucky, and all are people with have mental health and developmental disability labels, most of whom have spent the majority of their lives in institutions, who have posed challenges for other providers. Some of these people were already living in homes of their own receiving traditional supports and are now receiving self-determination supports. All people are living in the community, in homes of their own, with greater control over their lives and services, supported with individual budgets. A CLS administrator attributes the success of this program, in part, to the “strong spirit of support and gentle teaching” (Dehem, 2008).

Services for Older Adults and Adults with Physical Disabilities

CLS contracts with the Area Agency on Aging, the Senior Alliance, the City of Detroit and Allen Park, and the Information Center, Inc. to provide services to older adults and adults with physical disabilities living in Wayne, Oakland, Macomb, and Washtenaw counties. Through CLS, there is a network of qualified and experienced support service agencies. Individuals can chose the support service agency that best suits them. Available services include: community living support, community—based adult day services, personal care services, homemaker services, in-home respite care, home health aide services, home
delivered meals, environmental modifications and durable medical equipment, home maintenance, and Michigan Choice Waiver services (similar to those services provided within a nursing home, only in the person’s home). CLS currently serves over 200 seniors, all of whom are being served in ways that incorporate person-centered planning and self-determination.

**Services for People who are Homeless**

CLS offer services to homeless individuals and families living in the City of Detroit. In 2008, CLS assisted 94 families to move out of a shelter and into affordable community housing. CLS does this by helping families locate and move into permanent, safe housing and by providing resources that assist financially with rent subsidy, money management education, and locating and securing employment. CLS provides transportation to assist families to set up a household, get children in school, address medical needs, and reconnect with family and community supports. Supportive services are offered such as life skills training, substance abuse service and education, individual and family counseling, housing maintenance, job development, job placement, and the like. The approach of the program is to do “whatever it takes” to help families.

**Center for Self-Determination**

The Center for Self-Determination was established in 2000, under the auspices of CLS. The Center is a nonprofit collaborative organization offering technical assistance and training dedicated to advancing the principles of self-determination (Dehem, 2008). The Center has been a resource on self-determination for CSL, as well as for individuals, organizations, and many other entities nationally and internationally.
**LESSONS**

Based on challenges and successes, CLS has learned a great deal about organizational change and implementation of self-determination. They have been very reflective in much writing about what the key elements and are. Their summary about what it takes includes: changing mission and vision of the agency; leadership and stakeholder buy in; self-advocate and stakeholder involvement in new system development; communication, education, and training (Taverna, 2009). Some further lessons (also addressed in varying ways in other reports and documents) include:

- **There is need for clarity about what self-determination means within the context of the service system.** When self-determination was first initiated, it was not always clear to people with disabilities and families what that meant in terms of control of money and services. For example, one staff person reflected, “People thought that if they ate less, they could save that money and spend it on other things.” In this sense, their individual budget is not “their money.” They can, however, use their budget to make choices and decisions about the services they receive. Individuals and families have benefited as CLS staff have developed more clarity in the way self-determination is explained and promoted.

- **Conversion from a service to support model requires a changing role for residential service providers.** With the shift to self-determination, there is still a role for residential providers, as many individuals and families want assistance with managing their support staff. The role for residential providers involves a change from operating residential settings to assisting and supporting people to live in
homes of their own with the support of staff and other family, friends, and community members. At CLS, this meant assisting providers to make this change. In other organizations which provide services themselves, such a change could be made within the organization itself.

• There is need for organizations, such as CLS, that provide support coordination and promote self-determination, to work in partnership with residential service providers to help ensure safety and promote quality. For an entity such as CLS, which is working to promote self-determination, there is a critical need to work in partnership with providers. With providers no longer the source of a comprehensive range of supports within a group home, there is particular need for close communication and collaboration between various organizations and entities that are involved in people’s lives to help ensure safety and promote quality.

• Provider agencies must devise new ways of training, mentoring, and monitoring staff. When staff work together in group homes, it is easier for supervisors and more experienced staff to provide on-the-job training and mentorship. In contrast, when staff are working alone, with people in their own homes, provider organizations must create other opportunities for staff to share knowledge and experience. Similarly, when staff work together in group homes, it is easier for supervisors to monitor them. When staff are working in people’s homes, provider organizations need to ensure that monitoring continues to occur.

• The individual budget method as well as consumer based value purchasing has been instrumental in meeting the rigors of a long-term managed care system. Managed
care poses challenges to supporting people with disabilities, who have ongoing support needs. In particular, it is challenging due to fixed and diminishing rates for services. However, with the transition to self-determination and individual budgets (IB), costs have not risen. In fact, the average costs of self-directed budgets versus group homes as been consistently lower (the only exception being 2007, which was the first full year of a policy change of not paying for vacancies in group homes; group home providers now absorb some of those costs; at the same time, a premium staff rate is paid to self-determination budgets; at the same time, both self-directed and group home costs were lower in 2007 than in 2006). As people transitioned, living expenses been absorbed in a variety of ways: by live-in companions who pay a share; decreased maintenance and overhead; not paying for clinical services the person does not need or use. In addition, because people are more satisfied with their lives, this has translated into less need for higher cost interventions to assist people who are dissatisfied. As the IBs start out, there may not be savings right away, but down the road this typically starts to occur. Additionally, the individual budgets have fostered effective financial planning. As one administrator commented, “We have a reasonable handle on how much money we’re going to need for that particular year. We can look at our revenues and annualize them and I can tell you right now where we’re going to end up.”

- **Particular attention must be placed on helping individuals establish community connections and relationships.** As provider organizations shift away from managing people’s homes and lives, there is extra need for support brokers and direct support
staff to assist them in establishing a network of community connections and relationships, which can provide invaluable support to people as they pursue self-determination and self-direction, can contribute greatly to people’s quality of life, and can help serve as a “safety net” in times of need or crisis.

- For a large organization, assisting many people to move away from traditional services can be a very long process; at the same time, new individuals and new initiatives provide opportunity to offer self-determination and individualized supports to others. For a large organization, with many traditional group homes and other services, it can be a time-consuming endeavor to assist people in the move to their own homes and self-determination. This process can take several years or more, and requires a tremendous amount of commitment from an organization. At the same time, once the organization has mechanisms in place to offer self-direction and individualized supports, these can be offered to new individuals who come to the organization for assistance; additionally, through special initiatives, such as those undertaken by CLS, the organization can offer these types of supports in new geographical regions or to new populations of people (e.g., elderly, homeless).

- Blurred funding for day and community living increases flexibility. From the start, CLS/Oakland County has used blurred funding of day and residential supports. In this way, support people do not have to fit into narrow boxes in terms of what types of support they provide, and in what locations.
CONCLUSION

The organizational transformation that has occurred at CLS is due to their ongoing commitment to a vision of quality lives in the community for individuals with disabilities, as well as to the multiple strategies they have used to create change. Over the last 15 years, CLS, Inc. has demonstrated the application of principles of self-determination to organizational transformation. For them, this has meant not just changing one small aspect of the organization, but undertaking change in the organization as a whole. This sort of change takes a tremendous amount of time and energy; their work at this is ongoing. At the same time that they are working to assist the people they already support to transition from group-based services to self-determination, they offer self-determination to all new people who enter the organization, and they have created new initiatives to offer self-determination in different geographic areas as well as to different populations (e.g., people who are elderly or homeless). Their experience offers a wealth of strategies to other organizations, in similar or differing contexts and circumstances, that are seeking to begin a process of transformation in their organizations and in the lives of those they support.

REFERENCES


ONONDAGA COMMUNITY LIVING
A Story of How an Agency Changed One Person at a Time

By: Patricia Fratangelo, Executive Director
Bob Ciota, Deputy Director, CNYDSO
Michael Kendrick, Consultant

Introduction

This presentation is about an agency that previously provided traditional services that then changed its focus to more person directed supports. It is the story about Onondaga Community Living that is located in Syracuse that works under the jurisdiction of the Central New York DSO. Much of this story explains the dramatic changes that occurred within an agency that learned to listen differently to those who came to it for support. It is the story of how an agency reorganized because of this, what impact it had on its existing services and what impact it had on the development of new services.

Much of this work meant forging into new areas and breaking new ground to enable lives to look differently for people. Traditional "programs" were no longer the focus, new and more unique personalized options were being recognized and developed. Broader interpretations of traditional rules and regulations were pursued that would allow for more person directed options. A partnership had to be developed between Onondaga Community Living, those in key positions at the CNYDSO and with those at Central Office at OMRDD. OCL forged ahead with each new development one person at a time. Each person's story was different and each situation set up required different learning and atypical supports.

This paper will share some of the history of OCL and where it is at today as written by Pat Fratangelo, Executive Director of OCL. The paper will also share the perspective of Bob Ciota, Deputy Director of the CNYDSO in their partnership with this organization. Finally this paper will conclude with several comments from Michael Kendrick, based upon an 18-month study that he conducted at OCL on person centered supports. How it affected the agency and its impact on each person's life.

The History of OCL

When the current Executive Director came to OCL in 1990 the agency was operating group homes and involved with supported employment. There was no new development slated at that time. It was this Director's feeling that if anyone of the current residences wanted or needed something different in their life then OCL would do what it could to make it happen. At that time though the staff, families or people supported themselves thought that they were not skilled enough to live in an "apartment" setting or without others with disabilities.

New referrals began to come in. Since OCL had no property to fill, those at the agency began asking what each person would like to have happen. The planning began to ask some very different questions. Where do you want to live?¼not what slot OCL had to fill. Who do you want to live with?¼not this is the vacancy or the group OCL has for you to be a part of. What kind of support do you need and want?...not just typical staffing. What resources do you bring to the planning?...not just what OCL was going to do.

As OCL dug deeper into what relationships a person had, and what places and situations brought out the best (or worst) in a person, great information began to evolve. When OCL looked deeper into the vulnerabilities that the person had and the necessary safeguards that needed to be put into place, some interesting pictures began to emerge. People were not asking for traditional group homes or supported apartments, although they may have originally thought that was all that would be available. Many knew exactly where they wanted to live, some knew exactly the person they wanted to live with or have as a staff support. Others knew clearly that they did not want to live with others with disabilities.

So in the beginning stages, back in the early 90's, the new people coming in all began to be supported in some very unique ways. For example, the first gentleman was introduced to OCL when his mother was in her deathbed. She was leaving the home in trust to her disabled son. We were able to plan for his support while she was still with us, and set up daily staffing. He found a gentleman, also with a disability, that he wanted to share his home with. We also introduced them to a non disabled gentleman that would live there as a good role model and friend. His house was certified by OMRDD. How different his life would have been if we had moved him from his neighborhood,
away from the home he loved, away from the neighbors that knew him.

Another person had tried living in a group home and was injured to the point of needing hospitalization. By the
time OCL met him, he was back home living with his mother with the family stating clearly that he would never
move back to a place like that! Because of his physical needs and adult stature, his mother was no longer to
adequately care for his personal needs because of her slight build. When OCL really asked what she wanted, she
just wanted someone to help them out at her home and ideally help to get her son out to do things that other 24
year old men did. As we looked closer to all of his needs and what kind of support would be required, we then
asked her if she had anyone in mind to do this. She thought those at OCL were kidding! What? Get the support in
her home that they needed and have the person work with her son that they wanted? It was too good to be true.
As time went on though they were able to hire a full time support person of their choice and get back up support
through another organization for more of his personal care. They also chose this person. Seven years ago this was
developed and each of these supporters are still with this gentleman. The relationships they had came long before
res hab funding. Res hab funding now gives them an added benefit to spend the needed time with him that is so
necessary.

There are many more stories that can be shared but the important lesson to speak to here is the learning that was
happening at OCL. Originally people thought that to live away from a group you needed to be skilled. Now they
saw people who were often more needy that those in the group successfully making it in their own personalized
arrangement. So if it could happen for "stranger" that came to OCL, why could it not happen to those within OCL
that we knew well? One group of staff began to look at these questions and roadblocks carefully. Then one day the
House Director of one of the group homes came to the Executive Director and said, 'We think the people at Oak
Hollow do not like living together and that we need to look at different arrangements for them.' That simple
statement, then lead the agency down a very lengthy and complicated path towards a group home closure.
At this time now, in the year 2000, OCL has successfully set up personalized arrangements for thirty-six people.
OCL has successfully closed one group home and is currently in the process of closing another. OCL also
continues to provide supported employment and does so with one to one job matches in the community. The
agency has now developed a vocationally oriented Day Hab service that enables each person to volunteer in one
to one job matches in volunteer work in the community, giving them the actual experience necessary for a paid
position.
The focus of personalized supports is a thread that goes deeply through the agency on all levels. It is not just
another program type within OCL, it is now a way of doing business and of delivering supports.

CNYDSO Perspective

The Central New York Developmental Services Office, formerly Syracuse DSO, was first approached with the
notion of reconfiguring a supervised congregate community residence operated by Onondaga Community Living
at a point in time when the plan to close the Syracuse Developmental Center was in full motion. Agency (DSO)
resources were being directed in a priority and targeted manner to develop community placement outcomes for
the people who were living within the institutional setting. Although the proposed reconfiguration to more
individual and personalized community living options was intriguing there was immediate concern among district
managers over the potential cost, the ability to provide adequate and consistent staffing and support, and the
incongruence of closing a "group home" at the same time that these types of facilities were being developed to
accommodate the goal of institutional closure. In addition, there was no previous experience to utilize as a basis to
assess the adequacy or flexibility of existing funding options to support a more individualized model of personal
supports. As there were no other group home closures to look back at.
The availability of the Home and Community Based Services Waiver (HCBSW) did offer some opportunity to
individualize but even this funding framework was biased at that time toward the more traditional certified and
congregate type of residence. After careful consideration of the issues, the District Office made a decision to
support the development of a more specific reconfiguration plan within the following parameters:

1. The new configuration of service could not exceed the cost of the existing congregate setting;
2. The existing setting of the community residence would be made available for use by other residential
   service providers to address unmet community needs; and
3. Onondaga Community Living would be asked to assist in the larger institutional closure plan. If these
conditions were met, the belief was that the proposed reconfiguration could become a reasonable fit with the District's mainstream agenda, and as such attract support within the various review and approval levels of OMRDD's Central Office.

Once the decision was made to advance the proposal from the concept to design phase the role of the District Office became one of technical assistance and advisor. The posture shifted from telling the provider what could or could not be done to one of asking what outcomes were trying to be accomplished. The District staff worked closely with Onondaga Community Living to identify fiscal solutions that could be packaged to support person centered outcomes. All of the available OMRDD funding streams including the HCBSW opportunities, individual support service contracts, and family care were carefully explored in relation to each person's circumstance to craft a support package. In each case the regulatory funding requirements were carefully examined to insure compatibility between the individual plan and funding rules, and in each case it was evident that solutions could be crafted. This was a time consuming process requiring the attention of District staff in both the design and development activities, as well as the presentation and explanation to the OMR/DD Central Office and the Division of the Budget. In every case the proposed funding package was eventually approved. This experience demonstrated that it was possible to achieve highly personalized outcomes that could be supported within existing OMR/DD funding streams, although it is clear that existing pricing levels continue to favor the more congregate types of residential settings.

Comments by Michael Kendrick though His Work as a Consultant

The OCL experience is important for New York State. The agency's work constitutes a grass roots attempt within the state that explores what may soon come to be a growing dimension of the array of more personalized strategies of support in the field. The reason why this is important to look at is due to the way that services have been traditionally developed. There is a growing sense that conventional services, which have typically included the grouping of people, have simply not been responsive enough to the personal identity and needs of individuals. OCL's contribution is in the fact they have been working away at this concern on a small scale but nonetheless with notable and helpful results for the individuals they serve.

People with Disabilities Begin to Have More of Their Lives Given Back

Perhaps the most significant contribution that this agency can offer is that the various people served by OCL are getting a credible chance to be the kind of people they have the potential to become because of the way this agency has done services. This has been accomplished on several crucial levels. The first is that each person largely receives their supports from OCL in highly individualizing arrangements both at work and at home. Each person supported by the agency only rarely has to have what is happening in their life constrained or disrupted by what is happening for other people being supported. The reason this is possible is that OCL does not combine the people being served in order for them to be supported. In this way the consumers of service do not need to have the meeting of their needs so directly tied to what is or is not happening for other people served. This is not absolute, however, as all of the consumers draw upon the resources of OCL and thus collectively, distantly and indirectly influence what each other gets by way of support. Nevertheless, it is still fair to say that each person's (unique) pattern of support directly grows out of who they are.

The second important contribution of OCL is that there is not some kind of formalized or prescriptive planning process for individuals in the person centered planning genre. Rather, it is that OCL has tried to clarify and deepen the more important aspect of developing person-centered attitudes, beliefs and ethics. They continue to deepen this even further by working collectively with board and staff on retreats that dig deeper into the personal realities of individual lives. They regularly welcome visitors and evaluators, and continually open their minds to what others in the field both nationally and internationally are doing that work to improve individual lifestyles. This dimension of a personalized service is often just presumed to be in good shape as long as one has high-minded goals, language and intentions. Where OCL has significantly moved this question along is in presuming exactly the opposite! While OCL has such goals and aspirations it does not assume that these are achieved just because they are desired or desirable. It has had to recognize quite repeatedly that the lives of the people it supports are anything but ideal even where forward progress has been more than evident. It is also clear...
to OCL that a "personalized" set of supports does not automatically translate into better life options. In this sense, the supports may be individualized but the quality of what the person experiences as their life might still need work. It may even be that the overt individualization of supports hides failures to do the right or best thing. For OCL this means a need to constantly evaluate what has actually worked for the better. This means not taking things at face value just because they were well intentioned and inspired by positive goals.

OCL quite correctly believes that if they had better approaches to supporting people then the lives of the people they serve would be much improved from what they are today. They also quite rightly realize that person centered language alone or goals themselves are not enough unless there are highly deliberate intentions and actions to make it happen. This is not meant to mean that OCL has not improved people's lives in any number of important ways. On the contrary, they have been above average in this regard. What distinguishes them is that they do not believe they will ever be satisfactorily "person centered" since the lives of those they serve are simply too dynamic for OCL to ever get to such a point. In this respect they feel their work is never finished, with the overall goal of being person centered for each person never being met.

Instead they concentrate on the struggle for "person centeredness" as a problem not of outcomes alone but, even more so, a question of how to be with people in such a way that the person counts. In such a framework the personalization of supports and lifestyles becomes not a process of settling into the "right" model or pattern but more one of having to continuously undo and recreate patterns in people's lives so as to discover what might be better. This is "trial and error" on one level, as OCL does not have a formula for what is best. There needs to be a lot of guessing and therefore a lot of changing of minds and approaches. This kind of process is at first unnerving as it seems to imply that OCL lacks ideals and values and will simply do whatever is judged to be important on a given day. In some ways this is, in fact, what they do. However, this would be both misleading and incorrect. OCL does have overarching values.

Onondaga Community Living's mission is to empower and individually support people with developmental disabilities to live full lives as integral, respected members of their community.

We achieve this by:

1. Listening to and focusing on each individual
2. Helping each individual to build positive relationships with others.
3. Supporting each individual's effort to achieve personal fulfillment.
4. Exploring and developing ways to support each individual is his or her own personal pursuits.

Their mission provides a kind of anchor amidst the flexibility that they so intensely pursue and offer on behalf of people. This mission revolves around the worth of people as people and the need for each of them to have access to the same valued roles, lives and experiences in community life as do all other people who live in New York State. This is not so different than what any agency would espouse. OCL believes that they key is not their goals but the extent that these take hold in people's lives. This emphasis on translating hopes into practice with the person themselves as a guide is the heart of their sense of what their "ethic" is.

The attitudes and ethics the agency takes to make progress with people's lives is the heart of the process of learning to more deeply listen to and be guided by what people's lives are like and what they could be. The search for a good life for people means cultivating within oneself and the organization enough space and occasions for the many reflective, exploratory and sensitive discussions and other events that keep people's minds on who they serve and what it is that they might be needing. Sometimes this comes by way of the words or other communications of the person and those who love them. Sometimes it comes because someone is looking for the signs of what is being said but not spoken. It is difficult to find a single method that can achieve this and so OCL has much more concentrated on the developing the "way of being with" in which this is more likely to occur. By "being with" it initially means the answer to the questions of "what are we here to do?" and "how is this to be
Done?" But it goes further to the question of "what do we need to be like as people in order to do these things"? Providing support for people at OCL isn't a matter of following a job description but more an ongoing personal challenge to be the kind of people that are needed by the people OCL supports. Thus OCL tends to emphasize personal engagement, commitment and contribution with the emphasis on the personal. OCL knows that it is only as good as the efforts and qualities of each person involved. Consequently, helping people to do better has been a major investment of OCL. This is based on the belief that if the people supported are to keep growing the people doing the support also need to be growing and developing. They realized that their work would never be over as the people they served kept learning, growing and changing, much the same as none of our own lives are ever static or finished.

**Administrative Practice**

OCL also has discovered that the world of the bureaucracy and the need for good business and administrative practice is very important for establishing the kinds of stability and flexibility that they see as necessary for sound individualization of support. OCL has discovered that it is not necessary to temper one's vision in order to keep high administrative and financial standards and practices in place. Surprisingly, it has been the development of and the staying with of a vision for each person as having their own lives and supports that has given them the motivation and determination to persevere with the many obstacles that exist in any system to getting things done. The change they made as an organization is that the dedication moved from program type, to the development of services based on each person's life story and personal need. Thereby changing the nature and focus of their internal work and communications with the regulators and funders. In doing so, they have discovered all sorts of unexpected supporters of this vision of people having better life experiences including board members, families, neighbors, employers, the people themselves, public officials and many others. It has taught them that change also comes about one person at a time and it is important to look for the good that each person can contribute towards this goal.

It may surprise people how efficiently OCL is managed as many people equate vision with recklessness and a disregard for sound and conventional administrative practices. OCL has never found this to be true. It has discovered that while its programmatic directions may seem radical in a system that focuses too much on organizations than people, these directions are actually very practical. By concentrating on what is best for individuals there is more likely to be a better use of resources (ie improved cost benefit), more innovation due to the need for flexibility, more consumer and family satisfaction due to their greater influence, and increased outcomes due to the focus on getting more relevant personalized supports. All of this needs the presence of an administrative system that works efficiently so that people can concentrate on the more important programmatic questions.

**Vulnerabilities and Safeguards**

A third crucial level of progress made by OCL is in the effort to recognize and protect the things that are important for the well being of people as they go through the process of change. The vulnerability of all people, and often especially people who live with disabilities, is important to take into account and to positively compensate for this wherever this is practical. This ensures that the person is placed in less danger of unfortunate things happening to them. The people who support them as well as others who care about them play a crucial and usually irreplaceable role in becoming a key element of both defining and creating needed intentional safeguards. "Safeguards" are typically a mix of measures taken to ensure that a person's well being and potential have as good a chance as possible to develop. These are put in place to ensure that when risks are taken they are done so consciously and with a view to considering the person's best interests.

The kinds of vulnerabilities that are common for people served by OCL would be recognizable to many agencies. These include the normal vulnerabilities associated with all human beings such as concerns about health, safety, relationships, money, work, family, future options, etc. Then there are the kinds of vulnerabilities that derive from living with various kinds of functional limits associated with disability such as poor eyesight or hearing, unsteadiness, difficulty understanding some concepts, naivete' and gullibility, dependence on others, overprotection or underprotection etc. Additionally there are the effects on the person of living as a member of a group that society socially devalues. This includes low expectations, fear and aversion, negative stereotypes,
labeling, and so forth. Any number of actions might be needed to deal with these risks and OCL feels that good support means doing this as conscientiously as possible. Not everything can be foreseen and offset but maintaining reasonable vigilance can be achieved.

"Person centeredness" is for OCL not a matter of simply doing whatever is wanted by the person or those around them at a given moment. It is a struggle trying to discern what is "best" for people, as this is not something that is always so obvious. The whole issue of rights, risks and responsibilities is important not only at OCL but throughout the state. OCL also has to struggle with these questions and has found that this is impossible without also dealing with the "best interests" question. OCL has seen its role as to be committed to people and their best interests while at the same time letting the person be as central as possible to how this question gets answered. This is a very difficult ethic to maintain, as it is so easy for people in authority to organize and decide things in a way that suits their needs and wishes. OCL recognizes this danger but does not assume that it will ever be one that they can escape or avoid. There is always a risk with people that we see things through our eyes and not through the experience of others.

Consequently, many people have found that one of the chief sources of danger to people's well being might be the very people who care about and support them. This is more likely to be true when these people think they "know best" or feel that what the person wants or needs is something they "already know". For this reason OCL has realized that it needs to have safeguards against itself and the unhelpful tendencies it has as an organization. For OCL this has come down to trying to deal with its own shortcomings, limits and human frailties by acknowledging these as both present and as posing a problem. By being willing to examine its weaknesses OCL has been able to find better ways of dealing with them. This has not meant that OCL has eliminated its weaknesses at all as this is not possible. However, by focusing repeatedly on what is and is not working for the people it supports, its own shortcomings that need attention tend to get attended to. Equally, by holding many sessions to look at people's lives and hopes OCL finds itself continuously pulled back to better priorities and perspectives. If it let itself "off the hook" too easily this would be less likely to occur. Hence, for OCL it has proven important for it to become its own friendly critic.

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Facility Conversion and Beyond at The Arc Northern Chesapeake Region: A Story of Visionary Leadership and Strategic Planning

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BACKGROUND

The Arc Northern Chesapeake Region (Arc NCR) is based in Harford County, Maryland, a growing but still predominantly rural area northeast of Baltimore. The Arc NCR began as the Northern Maryland Society Parent Group, first establishing a privately funded, home-based sheltered work program in 1959. In the 1960s and 1970s, the agency opened a work activities center, a sheltered workshop, and three 8-person group homes. Then, in the 1980s, the agency was renamed The Association of Retarded Citizens of Harford County, and it initiated supported employment services and began conversion of group homes to three-person Alternative Living Units (ALUs). In conjunction with these initiatives, the Board developed a new mission statement: “To create opportunities for people with mental retardation to develop and exercise the competence that will empower them to make choices in the pursuit of their own personal futures and participate fully in the community.”

In 1990, the organization hired a new Executive Director, and developed a Strategic Plan for realization of the mission statement. Over the next 10 years, the organization closed the group homes, the activities center, and the workshop. Prior to 1990, the organization had begun work on closing the large group homes. Originally, there were three 8-bed homes, and by 1990 there were two. Altogether, by 1990, the organization had 54 people living in 12 places, including two group homes of 8 people each.

1This report is dedicated to Tim Quinn, a visionary and inspirational leader, who served as Executive Director of The Arc Northern Chesapeake Region from 1990-2010, during much of organization’s transformation.
When the new executive director came in 1990, he was clear that he wanted to close the activities center and the workshop, as well as continue with the group home closure. By 2009, the 54 people lived in about 32 different places. In 1990, the agency served 124 people with employment/vocational services: 34 (27%) in the activities center, 36 (29%) in the workshop, 19 (16%) in group supported employment, and 35 (28%) in individual supported employment. As of 2009, the agency served 201 people: 90 (45%) in individualized placements; 70 (35%) in crews; and 42 (20%) in volunteer work, recreation/leisure activities, and other daytime pursuits. Following all of this facility closure, agency administrators recognized that, based on their vision and strategic plan, the work to support people in more individualized ways needed to continue. Currently, as part of a Community of Practice, they are working toward developing more individualized supports and opportunities for self-determination for the people they support.

This report is part of a series of case studies related to organizational transformation. It is based on a site visit in September 2009. During the site visit, interviews were conducted with people supported by Arc NCR, family members, direct support staff, and administrators. The purpose of the report is to document strategies and challenges associated with organizational change.²

COMPONENTS OF ORGANIZATIONAL CHANGE

There are a variety of components to the organizational change that has taken place, and continues to take place, at the Arc NCR. These are described below.

²This report is part of series of reports on organizational transformation from facility-based services to individualized supports. All names used within the report are pseudonyms.
Visionary leadership and a Strategic Plan. A first and key step toward organizational change was the articulation of a vision and formation of a strategic plan based on that vision. Organization staff described the executive director as a “visionary leader” who continually sought ways in which the organization could provide higher quality, more individualized supports. Based on his leadership, the administrators and Board members agreed that by the year 2020, they would work themselves out of the business of offering traditional support services. According to the executive director, it was important to select a long-term vision, as he felt that, at that time in the organization’s history and culture, there would be less resistance to a long-term change than a short-term change: “Picking a vision 30 years out got a lot of people excited. Had we tried to do that in a 5-year period, we would have never gotten there.” Based on this vision, their Strategic Plan has guided the implementation of organizational change, including the steps and strategies discussed below. Agency administrators and Board members regularly revisit the Strategic Plan. The executive director remarked, “What still drives us today is the Strategic Plan we did in 1990.”

Group home conversion. Strategically, administrators decided that the best place to focus on conversion, following the 1990 planning, was with the group homes. As the executive director put it, “In all organizations, there are different personalities, and the director of supported living/residential services, was very eager to work on transformation, so that’s where we started.” Also, the sheltered workshop was bringing in needed revenue to the agency, so it was not the place to start.” In the next few years, the 54 people receiving residential services went from living in 12 places to about 32 places. National consultants and other outside resources were utilized to assist agency staff in learning about individualized
supports. While in-depth person-centered planning was not used with everyone, agency staff conducted individualized interviews and planning sessions in order to determine who people would like to live with and where they would like to live. The large group homes were owned by the Arc NCR; when everyone had moved out, the buildings were eventually razed.

**Activities Center closure.** In 1992, as a second step to agency transition away from facility-based services, focus was placed on the Activities Center. Of the 41 people in the Activities Center, 40 chose to leave. The Activities Center was closed, and the 40 individuals transferred to the sheltered workshop, where they could at least earn money while they were waiting for community employment options to be developed.

One person, Harry, who was 65 years old, wanted to stay at the Activities Center. The Activities Center was located in the same building as the administrative offices, so after the Activities Center closed and others had moved to the workshop, Harry remained in the Activities Center building, and staff who worked there took turns supervising him to do various jobs and other tasks around the building. Since the Activities Center had closed, there was extra space available in the building. Meals on Wheels approached the agency asking if they could use the kitchen to prepare their meals for delivery. For the last 7 years of his life, Harry, who had sometimes in the past been so angry that he had thrown rocks at the building, contentedly volunteered with Meals on Wheels, helping both to prepare meals and deliver them. According to the Executive Director, based on this experience with Harry, “agency staff learned an important lesson about commitment to people, and what can happen if you are open to the possibilities.” In addition, the Executive Director emphasized that this example also demonstrates the role of serendipity in individual and organizational change; while
planning is critical, even with the best planning, no one could have envisioned the relationship with Meals on Wheels and the role that this would play in Harry’s life.

**Workshop closure.** The next step in organizational change was to close the workshop. In 1996, the Maryland Developmental Disabilities Council (MDDC) issued a Request for Proposals for a grant to assist with conversion from sheltered work to community employment. Prior to submitting the proposal, the Executive Director sought a board resolution on closure. A key factor that helped in attaining this resolution was having the Board hear from self-advocates who already had community employment and who encouraged them to proceed with closure. The Arc NCR is a membership organization, with the general membership having the authority to elect the board of directors and to overturn board decisions and actions. Thus, the next step in the process was a membership meeting, at which the members opposed the board’s decision. Administrators recognized that the membership had not received sufficient information about how closure would proceed and the safeguards that would be put in place. An agreement was reached that the organization would proceed with closure, and that as part of this process, the executive director and the director of employment services would meet individually with all families.

The Arc NCR submitted a proposal to MDDC, and was awarded $75,000 a year, for 3 years, from 1996-1999. Administrators determined that they could likely find employment for all but about 10 people, a group of people with significant disabilities. So, they decided to use the grant funds to hire two staff to primarily focus on those 10 people.

In addition, the organization formed various committees to help implement conversion. These included: a Conversion Steering Committee (for providing overall
direction to and coordination of the conversion effort), a Marketing and Development Team (for planning, directing, and monitoring job development, placement, and support activities); an Alternative Day Committee (for exploring and developing integrative community activities for people who wished to retire or who were not currently working); and a Social Opportunities Committee (for exploring and developing integrative communities activities outside of the work place) (Wurzbacher, 1998).

In 1999, the workshop closed. Of the 51 people supported there, 12 went into individual work, 14 into work crews, and 25 others in various sorts of individual and group work experience and day activities. In addition, staff helped create many other opportunities for people between jobs, such as going to health clubs, and doing various types of volunteer work.

One of the people who found individualized community employment as a result of the workshop closure initiative was Jack, who had always wanted to work at the sheriff’s department. One administrator commented, “Before conversion, it just seemed kind of unrealistic when he said that’s what he wanted, but, when we put the effort into it with conversion, we were able to do it.”

Agency staff ended up finding employment (both individual and group employment) for all of the target 10 individuals. One member of this group was a man named Steven. He used a motorized wheelchair, he could read, and he used a computer with his elbow. Steven and the job developer agreed that a job doing mail delivery might be a good type of work to look for. The job developer investigated possibilities for this at Aberdeen Proving Ground (APG), a large military base. People at APG were receptive to the possibility of Steven working
there. It was agreed that he would begin on a volunteer basis for a few months, and that, if it seemed to work, then he would become a paid employee. As they began to actually develop the job for Steven they realized that he would need assistance in handling the mail. Steven had a friend, Pete, who had expressed the desire to never leave the workshop. However, when asked if he was willing to leave the workshop to come assist Steven with work, he agreed. Finally, they realized they needed another person to sort the mail, so a woman from the workshop, Lucy, was recruited to sort the mail. Lucy could not read, so the job coach developed a system of colored dots and numbers. For several years, until health issues arose, Steven, Pete, and Lucy worked together on this mail delivery job at APG.

While jobs were found for the target 10 people, there were another 10 for whom they could not find employment. Additionally, there were 15 others who were seeking volunteer work options or were interested in retirement. The agency instituted a “meaningful day” initiative to create individualized, meaningful daytime opportunities for these people. This might include participation at a community center or senior center, volunteer work, or recreational and social activities.

As people began to leave the workshop for community work and other opportunities, families who had been nervous about the closure became more supportive, and then even eager to have their son or daughter have this opportunity as well.

Overall, some of the specific strategies that were helpful in workshop closure included the following: (some of the information below is taken from Wurzbacher, 1998).

- **Work experience and exposure.** Staff observed that people might start a job with no idea about what was involved, and that this was sometimes a set up for a
difficult experience on the job and potential job loss. People had had little exposure to actual jobs. So, significant time and effort were devoted to helping expose individuals to people, places, and activities in the community, so they could make more informed choices, as well as supporting people to explore and try out different jobs.

- Creative financing and support options. Staff devised creative ways to pay for supports to assist people in community jobs. For example, they used PASS funds to pay co-workers. They also engaged in various sorts of fundraising activities. For example, according to staff, Steven, who worked at APG, had an old communication device that only said about five or six words or phrases, so he was very much in need of a new one. The agency sponsored several fundraisers and obtained matching funds from DORS (Division of Rehabilitation Services, Maryland State Department of Education) in order to purchase the new communication device. They also have used AmeriCorps workers to assist with providing direct support to people.

- Natural supports development. Project staff provided the initial training and support to people at their job sites. Over time, staff also worked to develop natural supports. Their success in developing natural supports helped them recognize the importance of developing natural supports earlier on in the employment process. Additionally, they realized that communication and cooperation among all paid and natural support providers was critical.
• **Entrepreneurship.** The agency made an effort to expand work options for people in the area of entrepreneurship. They involved Board members who had expertise related to this area. They determined that, for entrepreneurship to be most successful, it is important for the person to have a passion for the work.

• **Utilization of the Board as a resource.** It was important to reach out to and utilize Board members as a resource in the development of community employment opportunities. This was particularly relevant in entrepreneurship development.

• **The development and empowerment of Circles of Support.** Through personal futures planning, Circle members have been empowered to assist people in thinking about dreams and goals, and then to move to the pursuit of outcome-oriented, time-delimited changes. For example, Steven had a large and strong circle of support, including family members, church members, and co-workers from APG. One staff person recalled, “There were so many people sometimes that we couldn’t even meet in the home anymore, we had to meet in the church basement because it had grown so large, and it was just so exciting.” Steven’s circle members were very involved, not only in planning, but in helping his dreams come to fruition, such as obtaining the new communication device, getting a new wheelchair lift for his van, and so on.

• **Increased communication and cooperation among vocational staff and supported living staff.** Vocational staff and supported living staff worked together both on personal futures planning, as well as on implementing the changes that came out
of this planning. This collaboration prompted the organization as a whole to envision increased use of “services without departments.”

- **Increased use of direct service staff in conversion planning activities.** Direct service staff began attending staff meetings with the entire vocational staff; in addition, direct service staff members were involved in some conversion implementation activities. Overall, this helped increase their investment in the conversion process.

- **Increased use of outside consultants.** Outside consultants were used for assistance in planning, program evaluation, and circle facilitation. This provided staff with outside resources and sounding boards for developing and refining their conversion implementation strategies.

- **Increased focus on transportation.** The organization devoted increased financial resources to transportation, as well as increased time spent discussing and addressing transportation issues. There was recognition that the availability of transportation has a significant impact on people’s work options, as well as broader possibilities for inclusion and independence.

- **Focus on other activities in addition to employment.** In addition to employment, agency staff assisted people in finding meaningful community engagements between jobs or while they were unemployed. This seemed to markedly enhance people’s overall quality of life.
MOVING TOWARD INCREASED INDIVIDUALIZATION AND SELF-DIRECTION

By the end of the 1990s, the Arc NCR had achieved significant transformation. During the process of closure of their facilities, they had developed many examples of creative, individualized community living and employment supports. At the same time, in their effort to close the facilities, they recognized that individualized supports had not been developed for everyone, and that numerous people were part of work crews or were doing other community activities as part of small groupings. Thus, it was clear to them, after closure of their facilities that this was not the end of their hard work, but instead a new beginning of further work. They continued working to find more individualized community employment for those on work crews, and they continued trying to find other individualized meaningful daytime pursuits for people as well. However, they began having difficulties sustaining existing individualized options and creating new ones. Overall, in examination of and reflection about the organization, they realized:

- Some of the supports they provided that they had initially viewed as “individualized” were not as individualized as they had first thought or had become programmatized (e.g., the “meaningful day program”); they had not shifted much power and control to individuals; the agency still held most of the control.
- They had converted away from facility-based supports without having helped most people establish relationships and circles of support that would help sustain them in the community.
- There were aspects of the service system (e.g., inflexibility of some funding, separation of day and residential funding) that made it difficult to create and sustain individualized options.
This examination led them to revisit their vision and Strategic Plan, which resulted in further discussion within the organization and with others, statewide and nationally, about increasing individualization of supports and self-direction. This discussion led to the idea of forming a Community of Practice, whereby provider organizations could receive technical assistance, exchange ideas, and share information and strategies. The Executive Director was interested in the establishment of a Community of Practice based on his feeling that there is something significant about working on organizational change in the company of other organizations: “I think there’s something about going public with the intentions, to make your intentions stronger, and there really is some shared learning.” He approached the state Developmental Disabilities Administration (DDA) director with this idea.

In August 2008, the Community of Practice initiative began in the Central Maryland Region of the DDA (Scott, Hasbury, & Wykowski, 2010). The objective of this initiative is to form a learning community wherein providers, the DDA, and service coordinators can work collaboratively to create organizational and systems-level change that supports the development of individualized, self-directed supports. The Maryland DDA contracted with Neighbours, Inc. to coordinate the Community of Practiced and provide the associated technical assistance and training.

The Arc NCR was one of the initial five agencies to participate in this Community of Practice. The intent of this initiative is that organizations work simultaneously on creating change in the lives of some of the individuals whom they support, as well as creating broader organization-level change. The Community of Practice entails monthly meetings that incorporate training and technical assistance, as well as time for participants to share ideas.
about strategies and resources and to problem solve about organizational and systems challenges and barriers. Some of the specific areas of training and technical assistance include: person-centered planning, developing individualized budgets, fostering relationships and natural supports, creating increased housing options, ensuring people are selecting and managing their own staff, and supporting people to become actively participating citizens of their local community. As part of the Community of Practice, The Arc NCR has taken a number of steps to increase individualization and self-direction for the people they support. Some of these steps are described below.

Steps Taken toward Increased Self-Determination

**Hiring a staff person to focus on the change initiative within the organization.** When the Community of Practice initiative started, the Arc NCR had a group of core administrators involved. Soon after the initiative was begun, they determined that in order to most effectively create change within their organization, it would be necessary to hire a specific staff person to spearhead this change initiative. That person, Ann, currently works 25 hours per week, both assisting the targeted individuals in implementing changes in their lives (see below), as well as convening discussions and meetings with other agency staff about organizational changes.

**Meeting with the core team.** A core team of administrators was created to coordinate implementation of changes associated with Arc NCR’s participation in the Community of Practice. This team has been meeting monthly. In the future, the team will draw other staff, including direct support staff, into some of their conversations, to help broaden knowledge about and investment in this initiative.
Initiating individual change work. Ann has started coordinating person-centered planning for five people. Three currently live in their own apartments, with drop-in supports, and the other two share a licensed home. Either a MAP or a PATH has been completed with four of the five. The planning and work associated with it requires a significant amount of time, and many meetings and conversations with a wide variety of people. Ann will keep her focus on the five individuals until some substantial progress has been made toward some of their desired changes before shifting her focus to others within the agency. One of the people Ann is working with is Andy, who is 27 years old. He has lived in his own apartment for 5 years, with 10 hours per week of drop-in support. Andy would like to own his own home. Ann helped Andy pull together a circle of support, and they completed a PATH process. As a reflection of the importance of this to Andy, Ann commented that “He has his PATH hanging on his dining room wall.” Ann is helping Andy look at potential housing, as well as work toward meeting the qualifications for funding that would assist him with home ownership (e.g., the homeownership class). Based on her work to date, Ann anticipates that the system changes associated with this project will provide Andy with more choice and flexibility in his life. For example, as part of this project, people can hire people of their choice as support staff. Additionally, day and residential funding will be combined. Andy’s current staff are not always available when he wants staff support. So, he will now be able to hire someone who is available at the times he desires. Second, with the combined funding and the flexibility of the funding, Andy will be able to make different decisions about how to spend his money. For instance, he can potentially put less money into job support, which he does not need, and put
more money into transportation, so he can avoid the long bus ride that he now takes homes from work.

Forming deeper connections with regional housing organizations. An important aspect of Ann’s work is to connect with and form collaborative relationships with organizations that offer community resources. To date, the primary focus of this has been housing. Arc NCR has for a long time had a connection with Habitat for Humanity and some other county housing organizations, but Ann has spent time strengthening these connections, particularly in relationship to home ownership for people with disabilities. This has involved multiple meetings with Habitat for Humanity as well as another organization, Home Partnership. Additionally, she has met with representatives of Harford County Housing and Cecil County Housing. Some of the key learnings from these meetings include:

- **Housing resources.** Ann has been learning about different possible sources of funding to assist with home ownership, such as vouchers, individual development accounts, and first time home buyers money. Some of these may not always be available, and some individuals may not be eligible for them, but it is helpful for her to be familiar with the full range of possible options.

- **Homeownership classes.** For Habitat programs, people typically need to pass a homeownership class and get a certificate. After some discussion, it is clear that the director is very willing to consider adaptations or modifications to the class, particularly in light of the fact that some individuals would be supported by a circle of family, friends, and staff. Arc NCR is planning on offering a homeownership class for people who are interested in pursuing this option.
• **Other requirements of housing organizations.** In addition to the homeownership classes, some housing organizations have other requirements. For example, Habitat also requires that people volunteer to work on their house. However, Ann’s conversations with Habitat employees have revealed that they are willing to be flexible with this. For example, if transportation is a problem, a person could volunteer at another site; or if someone has difficulty with manual labor, he or she could volunteer in the office.

• **Income flexibility and employment plans.** Ann’s conversations with housing organizations also reveal that they are willing to be flexible about income guidelines, if people are relatively close, and consider contributions from family members and other sources. Also, housing organizations are willing to help people create an employment plan that could assist them to reach a goal of qualifying for home ownership.

• **Working out mechanisms for people to hire their own staff.** Ann is assisting people to develop mechanisms to hire their own staff. One of these is an interview guide, based on an individual job description that Ann is assisting each person to compile. Another is a written support agreement. The people who Ann is working with are very excited about the possibility of hiring their own staff; however, parents are nervous. The idea of having a written support agreement helps allay some of their concerns.

**Increasing communication with parents.** The agency convened a couple of meetings with parents to talk about self-determination and housing. The parents decided they needed
more of these types of meetings, and have formed a parent group and scheduled additional meetings.

**CHALLENGES IN MOVING TOWARD INCREASED INDIVIDUALIZATION AND SELF-DIRECTION**

Based on their past work at facility closure as well as their current continuing efforts at organizational change, they have identified some of the major challenges in working toward more individualization and self-direction in community living and employment.

- **There is a lack of consistently available funds to assist with home ownership.**
  Money that would help make housing affordable, such as first-time home buyer’s money, is unreliably available.

- **Individual budgets may diminish the agency’s capacity to create a pool of money to be used by people who are in need.** People’s money will no longer be combined at the agency level, so there are concerns that this may make it challenging overall for the agency to support people with higher levels of need.

- **It is sometimes difficult for individuals with disabilities and families to envision what individualized supports and self-direction will look like.** As with the closure of the workshop and development of community employment, some individuals and families may be hesitant to pursue individualized supports and self-direction because they have seen few if any examples of individualized, self-directed supports. However, administrators recognize that as some examples are created, this will help answer people’s questions and allay some of their fears.
• Organizations must be attentive, so that creative initiatives do not become programmatic. At Arc NCR, the “meaningful daytimes” initiative was at first a creative venture to identify individualized alternatives to employment. However, over time, it became a “meaningful day program,” in which some individuals were grouped together and stuck for long periods of time.

• There is a lack of funding and flexible supports to promote individualized employment. In particular, there is a lack of money to support people who need ongoing supports in individualized employment. Second, even when there is one-on-one funding, there is not funding for individualized transportation. Third, staff are used to supporting people in jobs during regular daytime hours, so it is more challenging to find staff who will or can support people who might find a job at another time of day. Finally, when the agency is engaged in job development for an individual, if that individual stays home, the agency loses money for that person; therefore, the incentive is to have that person participate in out-of-home daytime activities, whether or not that might be the person’s priority.

LESSONS RELATED TO ORGANIZATIONAL CHANGE

Additionally, based in part on their work at facility conversion, as well as their current continuing effort to transform their services, they have learned numerous lessons about organizational change. Some of these include:

• Creating sustainable change requires the organization to work in partnership and collaboration with people with disabilities, families, and other community individuals and organizations. The Executive Director reflected that in their past
conversion efforts, they had worked to create individual placements, but primarily without the assistance and collaboration of circles of support. This approach eventually became unsustainable. As he put it, “If I have to carry the commitment for 180 people alone, I can’t do it; the only way we can do it is in collaboration with families and circles.” Additionally, in their past conversion efforts, there was sometimes a feeling that change was being accomplished in spite of some of the inflexibility of the larger system. With the current Community of Practice initiative, the DDA is simultaneously implementing change that supports the conversion efforts. Finally, as the Arc NCR has become more closely affiliated with community organizations, they have been increasingly engaged in generic community issues affecting a broad population of vulnerable people, as well as those with developmental disabilities.

- **Individualized person-centered planning works, but it is a time-intensive process.** When agencies take the time to do authentic person-centered planning, with the individual, family members, and other support circle members, it is very effective at creating positive change. However, the culture of human service organizations typically makes this challenging, as such person-centered planning involves an intense amount of time and commitment.

- **It is important to shift toward looking at people’s lives as a whole, and combining day and residential funding to support this.** Their past change efforts, and struggle with sustainability, helped them appreciate the link between day and residential supports and the need to look at people’s lives as a whole. Although in the past the
Arc NCR has made efforts to work across departments, the larger service system still typically promotes a separation between day and residential services. So, for example, when an organization such as Arc NCR closes a workshop, many people who have part-time employment still live in residential settings that they are required to leave during the day. Thus, rather than having supports to assist them with individualized activities in their own home or in the community, they may be required to take a van to participate in a group volunteer or leisure activity. The flexibility of this project will help address these issues by combining day and residential funding, and looking across all possible sources of funding, in order to promote quality community lives across all dimensions (e.g., residential, employment, other daytime involvements, social/recreational, transportation, etc.).

- **Agencies need to assist people to be better prepared for an inclusive, self-determined community life.** As the Arc NCR has moved away from workshops and group homes, they have realized the importance of assisting people to be better prepared for employment and community living. So, for example, they created a summer jobs program for teens that gives them real experience with the routines and responsibilities associated with work; and, all people who receive residential supports now participate in typical household routines such as shopping and paying bills.

- **There must be a vision and a plan for organizational change; at the same time, some elements of change are serendipitous.** First, it is crucial for agency.
leadership to have a vision for change, an ability to engage other staff in this vision, and a Strategic Plan to achieve this vision. During the process of implementation, there will be many decisions, short-term trade-offs, and adjustments that need to be made. However, it is important to not lose sight of the overall vision.

Additionally, the steps and strategies used need to fit with the organizational cultural and personalities that are involved. Finally, serendipitous circumstances also arise that contribute to organizational evolution and change.

- **Families needs to be involved from the start.** Agencies need to go beyond just informing families about what they are doing. Families need information about and an understanding of individualized supports and self-direction. Additionally, they need to understand how they can play a part, what their role can be, what the agency’s contributions and limitations are, and so forth.

- **It is crucial for agencies to be open to an evolving understanding of “individualized supports.”** It is critical for organizations to be able to continually reflect on and revise their understanding of individualized supports, in order to examine the supports that are in place and work to assist people to increase the individualization and control in their lives.

- **Suspend judgments about who will be most challenging to support in the community.** Typically, it is assumed that people with substantial disabilities will be those for whom it is most challenging to support in community employment and community living. However, when concerted efforts are made to promote individualized employment and community living, this is not always the case, so it
is important to put such assumptions aside.

- **It is beneficial to undertake organizational change within the context of a Community of Practice.** As part of the Community of Practice, the Arc NCR has received many “nuts and bolts” of practical strategies and advice from the work of Neighbours, Inc. Additionally, as noted previously, they have found that it is helpful to have a group of organizations with whom to share commitments and strategies. Finally, involvement of the state DDA in the Community of Practice has helped promote systems change that facilitates the provision of individualized support on the organizational level.

- **Cultivating staff commitment to change is a process that will take time.** Before beginning a conversion initiative, it is important to get some key staff on board. However, it is also important not to necessarily wait until all staff are on board before initiating organizational change.

- **Communication and collaboration with community organizations can help eliminate real or perceived barriers to inclusive community living.** For example, in meeting with and gaining more information from housing organizations, it was possible to learn about flexibility with regard to potential barriers, as well as cultivate relationships that may be helpful in overcoming other barriers.

**CONCLUSION**

Over the past 20 years, the Arc NCR has achieved significant transformation, both in terms of facility conversion as well as continuing effort to work on transformation toward more individualized supports. The most important lesson they learned following facility
conversion was that closure is not an end point, and that following facility closure it is essential to remain open to further possibilities for change toward increased individualization and self-direction. One of the keys to this continuing change has been the formation of a Community of Practice in which organizations and the state are working collaboratively to create both organizational-level and systems-level change that facilitates the development of individualized supports. Another key to this continuing change at Arc NCR was having, as described by organizational staff, a “visionary leader” who continually prompted the organization to reexamine its practices in order to best promote quality lives through individualized supports and self-direction.

REFERENCES


Welcome

How I worked myself out of a group home

Brad Jones

Introductions

Journey

After 8 years in an institution,

My family helped start a group home where I could live with others

I needed peace

I needed support people to listen to me

I needed it to be on my terms
I discovered Facilitated Communication in the early 1990's.

Finally I could say "Get me out of here!"

Still spent years finding typing partners.

Still needed peace.

Still needed support people to listen to me.

Still needed it to be on my terms.

In the late 1990's I moved from the group home.

I tried shared living arrangements with one or two other people.

It still wasn't what I was looking for.

I moved several times.

Still didn't find what I was looking for.

People thought I was being difficult.

I thought people were crazy!

I knew what I wanted.

I was insistent that I wanted it.

I kept it up until they understood.

It was the only way.
Journey

I wanted a home.

Journey

We spent a year planning:

They promised....
   I would be in charge....
   I would hire people....
   I would pay them....
   I would do schedules....
   I would do training....
   Everyone would listen to me....

Journey

I still thought they were crazy!
Journey

So did Mom!

The Plan:

TLC would help coordinate everything I needed
TLC would teach me how to lead, and the staff how to follow
TLC would help manage the staff schedules and my supports
TLC would help me with emergencies and safety

I would have an apartment I shared with a community roommate (not staff, not a person with a disability)
I would make my own decisions, with support
I would establish my own life, in my own home.

The Move:

I moved to Kent in 2000 and learned to do all the things they said I could. And more!

My support people were starting to listen to me.
My life and my home were starting to be on my terms.
I was moving toward peace.
This is a journey.

I'm not done yet.

I had a home!

Journey

I was trying to find peace.

I was trying to tell them what my terms would be.

Finding the right support people was the hardest part. It took almost 4 years of my support people not understanding what I needed.

Journey

Twice, out of frustration,

I fired all of them.
Journey

In 2004, my support people became TLC employees.

Now I had more assistance running my own supports.

This partnership was a crucial turning point.

And created what I have now.

My Life

Now, I've got it!

A home of my own!

A life on my terms!
I have Peace!

As long as I have a home

Most important thing I can do for myself
Every day I find more happiness.

LISTEN TO ME

reassurances
routines
calm
fun
LISTEN TO ME
I want reassurance from people I trust.
Many times I find, without doing things,
I mean, and it makes you want to feel.
I want to feel to be comfortable.
I have a lot of time to pass.
I'm a good guy.
my view

getting sun and watching the neighbors
music and dance

solitude, reflection, rest

and don’t forget the couch...
I love to draw, color, and do things with my hands.

and like every guy, I get to put my feet up AND control the remote.
I get support to send my family e-mails

and write brilliant speeches
fine dining with a view

The experience of the creation of my life

How I worked myself out of a group home
The experience of the creation of my life
The experience of the creation of my life

Thanks!

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Some lessons concerning agency transformation towards personalised services

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Abstract
The International Initiative for Mental Health Leadership (IIMHL) is a joint endeavour involving eight countries, and aims to facilitate the sharing of best practices and to provide support and collaboration for leaders of mental health services to develop robust and effective managerial and operational practices. The ultimate aim is to improve services for people who use them. An article from the IIMHL is included in every issue of The International Journal of Leadership in Public Services.

This paper describes the key learning outcomes that came from the examination of the experience of eight American community-based agencies that altered their service practices from an exclusive reliance on group and fixed models of service, to models of service that were exclusively individualised for the entirety of the people they served. It examines the key lessons learned as to what drove this process and what did not, as well as what some of the critical comparative outcomes were. A significant core factor cited repeatedly was values-based leadership from within the agency concerned and a key result was that individualised services for every person served were very cost competitive in the systems they were in.

Key words
international; agency transformation; service models; support; personal and organisational leadership

The challenge of the individualisation of services
Many service models are quite set or fixed in nature so that a kind of standardisation of practice becomes entrenched. If the service model and subsequent practices become rigid and entrenched, then there is a very real likelihood that the service will persist with upholding its service model ie. its fixed pattern of practice, irrespective of whether it meets the specific needs of the people that might rely on that service or not.

This might not matter if the needs of the persons served were themselves quite alike and standardised, because a set or fixed response that was relevant to such needs would make sense, since there would be symmetry between what is needed and what is provided. For instance, if the service was set up to deliver a relatively straightforward intervention, such as explaining a new systems eligibility criteria to prospective service users, then a standardised approach would likely work reasonably well.
Hence, there may be at least some merit in a closed and limited ‘menu’ driven service model.

However, as human needs become more complicated and diverse in nature, it becomes increasingly more appropriate to alter service responses to more precisely fit the specific needs that are present or emerging. This avoids the dangers of providing supports to people that are irrelevant to their specific and unique needs, of offering the wrong degree of potency of support and even possibly damaging people because what is offered is somehow toxic in terms of its effect on them as it is contrary to what they need. Nonetheless, a good number of our services today are not responsive in this sense and this will result in the person being fitted to the ‘set’ or ‘fixed’ service model rather than the service model and practice altering in accordance with what is actually needed by the person. The service model perpetuates itself, rather than changes, to meet the varying and specific needs of those seeking service.

The response to this challenge has often been seen as a need to create the types of service models that essentially guarantee a targeted individualised response to the specific and unique needs of each of the persons being served. Further, a service model is needed that results in distinctly individualised options on a person-by-person basis and that these are driven by what the person needs. In its most systematic expression, it may mean some measure of capacity to design individual solutions to the person’s needs that are built from scratch or built from and around the person’s needs.

**The necessity of agency transformation**

To achieve such widespread individualised outcomes would require the presence of agencies that could transform themselves from standardised group and fixed models of services to individualised ones, or the deliberate formation of new agencies whose service models are essentially individualised from day one. Given that the vast bulk of current human service resources are already invested in the former, it is easy to see that if the goal of there eventually being significantly more individualised tailor-made options available on a widespread basis is to be achieved, at some point we would have to be able to convert the present stock of fixed model services to ones that routinely create individualised options.

Otherwise, one could only individualise with new monies, since all of the old and recurrent monies are tied up in fixed models.

Should these funds not be able to be unbundled from conventional service models and be in turn spent in individualised options, then no system would be able to deliver individualisation except to the few who were able to access new monies. There are obviously a good number of community agencies in existence that are now using recurrent funds in creating exclusively individualised options, but they may have skipped the phase of converting from group to individual options since they had essentially started with individual options rather than converted to them.

**The need to examine the evidence offered by existing examples of agency transformation**

It is precisely this question of whether agency transformation of this kind can take place under real world conditions that is at the heart of the question of whether individualisation could survive as a credible goal of service systems. On another level, if community level agencies cannot actually first convert from fixed models of service to individual options, then personalised service options will progress no further than being goals that cannot get implemented. Further, if these same agencies cannot individualise for all of the persons served without exception, then there is a risk that individualisation is only viable for some, but not all persons served.

Further, if the agencies then found that they could not sustain individualisation indefinitely into the future, then this might suggest that systematic and widespread individualisation is impractical. Finally, if it was only agencies in specific jurisdictions that were able to succeed, or in specific financial, bureaucratic or political regimes, then there would be the question of whether or not individualisation was feasible across multiple environments, some of which may be more or less favourable to upholding individualisation.

The only way to know for sure whether these feasibility questions could be answered affirmatively in favour of individualisation would be to locate agencies from multiple locations and jurisdictions that had successfully transformed themselves from group to individualised options for each and everyone they had historically served in group models or that they had drawn from group models. Further, such agencies could also demonstrate that they could sustain individual options for a sizable time without any interruption of individualisation.

If such outcomes could be achieved by even a handful of agencies, it would suggest, at least,
prima facie evidence that at technical performance and possibly other levels, systematic agency transformation towards individualisation could be potentially feasible if other agencies faithfully followed the same approaches taken by these pioneering agencies.

A special conference to examine the experience of demonstrated long-term agency transformation

With this question of feasibility in mind, the North Carolina Developmental Disabilities Planning Council hosted a four-day national conference in May of 2007 in Asheville, North Carolina to showcase a sample of agencies from within the United States that together met the criteria already mentioned. Led by a small group of conference planners, it was decided that eight agencies would be selected that had already engaged successfully in agency transformation and had demonstrated that it was able to create an individualised option for each of all the people it served without exception and that it had been able to sustain and evolve these for a minimum of at least a decade. Lastly, it wanted agencies from a wide variety of states in the country.

Eight agencies, from both urban and small town locations in seven different American states, were selected as being examples of successful pioneers in agency transformation towards individualisation. These states were California, Louisiana, Massachusetts, New Hampshire, New York, Washington and Wisconsin. Some of the agencies had, in fact, been totally individualised for 20 to 30 years already and some were more recent, but all of them had been totally individualised for at least a decade. Individualisation was judged to be that each person served had a distinct individual support arrangement. The agencies were all from the disability sector and principally, though not exclusively, served adults. They also had a mix of residential and day/work services, as well as other foci such as family support.

Each agency was asked to provide a detailed profile of the basic facts about itself so that its lengthy plenary presentation could focus on its description of how it had precisely transformed itself in the direction of individualisation. This was followed by an opportunity for those persons in attendance at the conference to question the example agencies on any matter that was of interest to them, both in plenary and informally during the conference. Each agency essentially had almost a half day to tell its story.

In light of the fact that even with these generous amounts of time, not all questions or aspects of agency history could be pursued to the extent that would satisfy the inquiries of some conference participants; it was offered that such participants could continue with their inquiries directly with the agency after the conference was over. It should be noted that the conference organisers did not independently evaluate the many facts and claims of the agencies, so it is conceivable that some of their portrayals of themselves might not be entirely accurate in every respect. To have done so would have been hugely expensive and time consuming and would have been a divergence from the main aim of the event, which was to explore, in an initial sense, what might be involved in actually achieving widespread individualisation.

Some of the key lessons highlighted by the example agencies

What follows here are some of the more notable lessons that these example agencies repeatedly demonstrated. They are presented here only very briefly, so as to give an overview of what their experience had demonstrated. Obviously, such a thumbnail sketch is inadequate in properly conveying much important detail or in explaining what might account for the patterns observed. Nonetheless, it does point to factors, assumptions and theories that may challenge much of what may be presumed about the individualising of services by persons who have not yet actually accomplished it.

The agencies had individual options in place for the entirety of the people that they served

The agencies had found that they could transform group and fixed models of service to individualised options and that they could do this with all of the people that they had been serving and sustain these indefinitely. They were all careful to point out that this had not always been easy, nor that their efforts at individualisation were always of good quality. They all described the task as challenging and full of struggles and setbacks. Nonetheless, despite these and other caveats, they all reported that they were convinced that wholesale individualisation of this kind had proven to be feasible for them. No agency declared a sub-set of individuals as not being feasible for individualisation.

No agency had reverted back to providing group or fixed models, though there were a few instances of some individuals who had elected to opt out of their services and who re-entered conventional services.
In every instance, the agency had offered to continue to serve the person in an individualised arrangement. As such, they had not broken with their commitment to individualisation, but did respect the choice of the person to go elsewhere. It is notable that the people served represented a largely stable group that had been served continuously over time by the same agency.

Agency level individualisation happened in service systems that were largely not pursuing extensive individualisation

It may be assumed by many that individualisation at the agency level can only occur if the whole surrounding system is pursuing this goal simultaneously, on the premise that an a priori systems commitment to individualisation is a necessary precondition of agencies being able to individualise their services. In fact, the agencies that presented were often either the only agency they knew in their state who had entirely and systematically converted from group to individual service models or that the number of other agencies that had also done so was very small. It is notable that these agencies coexisted right alongside other agencies that had no specific interest or commitment to individualisation. More often than not, these agencies were the initial early adopters of individualisation and were in the extreme minority in comparison to agencies that largely relied on group or fixed models of service. Nonetheless, these agencies were thriving and succeeding, in terms of what they offered service users by way of tailor made options despite their embrace of a very divergent path relative to the majority of agencies.

The impetus to individualise principally came from values-based leadership within the agency

The assumption that some people might make would be that individualisation would arise only as a response to systems mandates and that agencies that proceeded without it would be stymied by such a system. This was not the case whatsoever with these example agencies. The decision to individualise came entirely from within each agency, though some of the agencies acknowledged that they had been deeply influenced and inspired to do so by people and examples external to them. What seemed to have been decisive in each agency’s story were the values and leadership of key people in the organisation, both solely and collectively who championed the goal of agency transformation towards individualisation and helped overcome whatever stood in the way of this occurring.

In most instances, the decision to entirely individualise their supports was controversial and even divisive internally. Further, their individualisation approach often was not a normal provision of the system, so the agencies often faced the need to collaborate with their funders and others to find a way past whatever bureaucratic hurdles were in their way. Frequently, they were assisted in this task by people in bureaucratic and systems roles who supported their aims. Nonetheless, the principal driver was internal agency leadership that emphasised the values of personalised supports, with the agency directors being a key component of this.

All agencies believed that they had achieved what they had with individualisation by simply moving ahead with individualisation one person at a time, no matter what

The agencies did not emphasise the outcome of systematic individualisation so much as their method of advancing by engaging and resolving issues with a given person one at a time. As each person’s situation became more individualised, this helped lead to the more macro net result of increased overall individualisation of lifestyle and supports. In another key sense, the agencies were asserting that each individual being supported constituted a key test of responsiveness by the agency to that person’s needs at a given moment. Should the agency fail to be of help, then it would mean that the person would do less well. So, for these agencies, the concern was not whether a response was individualised, but rather whether this response was relevant, effective and beneficial.

No agency believed that they had been given, or had they expected any guarantees in advance from the system that their individualisation would be supported

Though many agencies might prefer to be reassured in advance that they would face any risk or tribulation by entering a change process, such blanket assurances are not likely to be offered by any system. It is noteworthy that these agencies did not expect nor did they pursue such assurances. In each instance, they went ahead simply on the conviction that this is what the people they supported most needed and wanted and they would pursue these aims on that basis.
In this regard, these agencies recognised that they would have to act as trailblazers and pioneers and that would mean undertaking a sizable measure of sacrifice and challenge on their part. In this, they also recognised that they might well be the odd man out in their system and were willing to accept whatever price they might have to pay for this. At the same time, they did repeatedly acknowledge, with considerable gratitude, the support and encouragement they had received from many people both in and outside the system on both official and informal levels over the years.

The net costs of individualisation in the aggregate were within the range of normative per capita costs in that system

A common objection to the proposition of widespread individualisation is that it would not be affordable, i.e. the presumption being that group services are inherently and inevitably cheaper. Undoubtedly, much of this thinking is premised on the idea that all individualised services would have as a basis, one-on-one staff on a 24/7 rotation cycle. While most of the agencies did have some such arrangements, it was notable that these options were only some of the mix of supports that they had developed. Consequently, when their overall costs were averaged across all of the people they served, the cost per person was comparable to or less than the average per person cost of service, (in the system they were in), for people with relatively similar needs.

All of the agencies had been able to maintain a balanced budget throughout the entirety of their period of individualisation

Though the agencies had better and worse financial years and were subjected to the same cyclical financial circumstances faced by all of their peer agencies, they had never failed to maintain a balanced budget on a year-by-year basis. Though many agencies that have not tried systematic individualisation might fear that it would somehow break the bank, this did not seem to be the case at all. The agencies did acknowledge that they had had to be extremely frugal and intensely fixated on their goal. Further, they acknowledged that they often had to make many sacrifices in order to achieve their goals. However, they saw this price as an inevitable cost of creating change for the better and were willing in most instances to do whatever it takes.

All of the example agencies were fully compliant with system and funder requirements

It is conceivable that some people might presume that going down the route of individualisation would be so anomalous that the agency might imperil its ability to be supported by the broader system due to a failure to comply with its requirements. This was not the case – not one of the example agencies had had this experience. Rather, they all reported being in good standing with all of their funder and system requirements and most reported being in the exemplary compliance category in regards to these. This is not meant to suggest that these relationships were always easy and harmonious, but rather that they were well within the normative range. Put another way, while some people might have seen their service model preference for individualisation to be radical and even somehow risking the disapproval of the authorities, this did not turn out to be true in practice. More common was that the funder often, but not always, saw such agencies as being welcome leaders and innovators.

The agencies were comparatively small

These example agencies were notable in that they were relatively small in size and in some instances, quite self-consciously preferred to be small due to their belief that the quality and viability of their efforts at individualisation were better if the size of the agency did not get too big. The largest agency of the eight had a budget of $14 million. Most were considerably smaller. Presumably, transforming a smaller agency might be easier to achieve than might be the case with a bigger, more complex and possibly more entrenched agency. Further, it is notable that no agency larger than $14 million in budget size was identified anywhere in the United States that had successfully achieved the same systematic individualisation as these smaller agencies had. Such agencies might conceivably exist, but their identity had not been pointed out by any of the available informants that were asked.

Consequently, the conference organisers were unable to find a single example of a larger agency, at the time of the conference, that had either specifically committed to such systematic individualisation, quite apart from achieving it so that all persons served were now exclusively in individualised options. Only one of the eight agencies was somewhat large in size in either financial or the number of people served senses. Many large agencies that had some examples of individualisation were noted, but typically these
agencies had not chosen, as yet, to systematically individualise services. Not unexpectedly, what was discovered to be in considerable abundance was person-centred rhetoric and goals, but this did not seem to be associated with the actual formation of systematic individualised options. This made it all the more interesting as to why at least some agencies had been able to do better at turning goals into actual person-by-person support arrangements.

Respect for and effective engagement of families and other natural supporters
Most of these agencies emphasised the valuable contributions that families and others had made to the lives of the persons being supported. Rather than portraying families as burdened and in need of respite, they typically saw families and others who played family-like roles as being a potentially invaluable resource that made supporting the person much easier on many levels. On another level, these agencies saw that the contributions that families and other natural supporters made were particularly important. These included freely given relationships, commitment, independent advocacy and safeguarding and access to broader community networks and membership groups. In addition, many families gave exceedingly of their time and monies towards supporting the lifestyle of their family member with a disability. Not all families are equally positioned in either time or money, but they often give of what they do have in good measure. Inherent in these recognitions of family contribution is the value of agencies entering into and upholding good partnering relationships, so that the service user would have both what the agency could offer and what flowed from family and community ties.

The agencies served their share of very-difficult-to-serve persons
The agencies were able to serve people that were considered by most people to be very challenging to serve on an ongoing basis and none reported abandoning such persons in order to make it easier to individualise. In fact, the agencies were pleased that they had been able to support such persons, as they believed that it was both a testimony to the values that they embraced and the fact that most of these people were eventually doing much better in individualised arrangements than they had been doing in more conventional ones. They emphasised that achieving these sorts of results had been taxing in all sorts of ways and that it would be wrong to conclude that, even at present, they were still facing many struggles to get things right for particular individuals. As such, their claim was that they were managing nonetheless to support such persons within individualised support arrangements on a sustained basis.

All of the agencies had in place some form of functional individual budgets
The premise, at least in some circles, is that the individualisation of supports is impossible except in systems that overtly provide individualised funding to individuals. Others might assume that agencies would not co-operate with individualised support arrangements except in instances where this is forced on them due to the service user being in control of the purse strings. It is notable that, in the case of these eight agencies, the agencies not only supported individualisation, they saw themselves as champions of it. They also had no apparent difficulty maintaining a set of internal individual budgets that divided up systems resources such that each person’s costs of service were linked to their unique personal needs and priorities. In most cases, these were informal budgets, but workable nonetheless for purposes of planning, implementation and partnering with the agency.

All agencies were able to coexist and thrive throughout multiple changes in political parties, administrations and policies
The longevity of the period of systematic individualisation across these agencies varied from 10 years to over 30 years. In the intervening time in these seven states, there had been regular changes of state and federal political parties, as well as an ongoing change of bureaucratic leadership at both the state and federal level. The systems around these agencies were in constant change and these changes did not seem to have been ultimately fatal to the agency’s pursuit and sustenance of individualisation. This is not meant to suggest that some of these changes had no effect whatsoever on their practice of individualisation, but rather that the agencies eventually found ways around whatever adversity they might have created. In reality, some of these changes were serious enough in their consequences to potentially imperil individualisation. Even so, it is notable that none of the agencies had thus far been ultimately stymied in their efforts to individualise.
All agencies saw their principal task as developmental and ongoing in regards to a person’s life at a given moment
What was happening (or not) in people’s lives and their resultant needs were what dictated priorities for the agencies. Their emphasis was not on simply starting a given individual support arrangement, but rather the challenge of being able to address whatever might come up in people’s lives. All of the agencies emphasised that upholding a person in their lives was a constant challenge as life was continually changing for the people supported, and the agency had to usefully respond to these changes if it were to remain faithful to the person and their well-being. Thus, the agencies did not believe that by individualising services they had somehow arrived at a point of success and could, therefore, relax. On the contrary, the individualisation of supports was merely the beginning of their continued involvement with the person and the issues that arose in their lives.

All agencies believed that vision and values for people’s lives were much more important than money as a determinant of good person-centred outcomes
Though it is not hard to find people who claim that they would do better with people’s lives if they had more monies available to assist them, this was not the consensus among these agencies. Rather, their belief was that the key factor in shaping good outcomes for people began with and was guided by the clarity and positive nature of their vision and values and whether these were meaningfully applied in people’s lives. They were appreciative of being able to access financial resources and would not claim that monies were irrelevant. Rather, they instead emphasised the qualities of the people they enlisted in paid and unpaid roles and the impact of these qualities on the sense of hope and promise in each of the lives of the people supported. In this regard, the agencies believed that they had better than average staff retention and took great care to select, keep and nourish the people that brought the qualities they most admired and enlisted in their support of people and their lives.

Conclusion
This conference was instructive, both for its clarification of what the active ingredients are in achieving widespread, if not systematic, individualisation of supports, and lifestyles from a base where the majority of people supported are in fixed group service models. In this regard, the conference’s emphasis on personal and organisational leadership and the role of vision and values is notable as key precursors to embarking on the person-by-person pursuit of individualisation. This is in striking contrast to the belief that only systems can create individualisation and that people and agencies must wait until such systems make up their mind. Further, despite the widespread presumption that individualisation would be unaffordable in most systems, these agencies have demonstrated that it is actually quite feasible financially providing that the given agency is frugal, determined and emphasises the role of quality in those who provide the support. This will be good news for those people who still seek the possibility of each person having a unique lifestyle and supports.

Note
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Addenda A
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A Place of Our Own

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BRAD JONES

Total Living Concept, Kent, WA
A Place of Our Own

Darla Emerson, Bradley Jones, Lyle T. Romer, and Mary A. Romer

For many years now TASH has been engaged in the struggle to assist people with significant disabilities to leave large, state and privately operated institutions and create a new life in the “community.” Institutions are not a proper place for anyone to live his or her life. However, over time, we have come to venerate the “community” as an absolute good. In fact contrasting institution versus community has led us away from something crucial in the lives of the people with disabilities: a home of their own.

Arriving in the community is not enough. The community is too large, too heterogeneous a variable to compare to institutions. Of course, the community offers far greater opportunities for people with disabilities than any an institution could ever offer. But, for many people that is all the community becomes: a set of opportunities gone unrealized. Like it or not, being “placed” in the community, in and of itself, offers no guarantee of a successful or fulfilling life (Wolfensberger, 1975). Charlie Galloway warned us years ago about trans-institutionalization. I don’t think we got the message then or now. His message still eludes us in far too many people’s lives.

A Placement or a Home?

We would pose a simple question to illustrate our point: how many people with significant disabilities live in a home or their own, as contrasted with being congregated in admittedly small scale but none-the-less segregated housing? How would we know the difference? Typically when people are “placed” in the community there is a very high probability they will be living in a house or apartment with two or more other people over whom they have no choice. This ignores one of the most important aspects of creating a home of your own: the ability to shape the environment, both physically and socially, to reflect one’s interests and preferences. We believe, and have learned from listening to people with significant disabilities, their families, friends, and those who provide daily support that home consists of more then just an address (Watson & Austerberry, 1986).

What we have learned is to think of home as a set of relationships deeply rooted in a place. This place consists of walls that both include certain people and possessions and exclude, temporarily or permanently, certain other people or things. The physical location of this place and how it appears are important aspects and nothing defines home like the sense of self it provides us. We define who comes into our home, how long they stay and what they do while they are there. It is the one place where we have the most influence over our lives. We often refer to this as being the keeper of the threshold. This, to us, is the central defining point of home. From this flow other, important aspects: the sense of refuge and renewal provided by home; the ability to relax and be ourselves more completely then most anywhere else; the ability to engage in intimate relationships with others of our choice; the simple opportunity to be alone and cherish our privacy; and, the ability, by our invitation to others, to offer them hospitality.
The fact is we don’t really know how many people actually live in a home of their own. Our best available data are those provided by Braddock and his colleagues in the State of the States in Developmental Disabilities (Braddock, 2002). This report indicates how many people are living in groups of six or less. It does not indicate whether these living arrangements are with others receiving support through their DD system or with housemates of their choosing. The mere omission of this type of data is reflective of how little importance is given to the true concept of “home” versus living arrangements.

We would like you to consider the feelings of the first author of this article and her efforts to make a home for herself.

- Imagine living in a group home where you have no decision-making power and choices are not part of the plan.
- Imagine not being able to choose your roommates, your furniture, or even how your room is decorated.
- Imagine not having control over what you ate, visitors, or even your own bathroom time.
- Imagine being a teenager living in a nursing home.
- Imagine life without choices, without a place you felt was home.

This was I until 1990, when at 17, I got to leave this life behind and actually begin to have a life. I went right from the nursing home and having so little control to my first home and having so much control and decision making power that it was a little scary.

I first moved to an apartment in Kent, Washington with two roommates. All 3 of us used wheelchairs and what I found was that I really didn’t like one of my roommates and our living area didn’t work well for all 3 of us. It was too busy and crowded. After what seemed an endless wait, I got Section 8 housing. With this I had options.

I now have a 2-bedroom 2-bath apartment, which I have furnished. I selected and purchased these items. I directed how I wanted my apartment decorated and where things would go. My apartment is an expression of me. I find joy and peace. I love my apartment. Its here where I can dream and think about my life, reflect on the past, think about the here and now and plan for the future. Group living with chaos and no choice is not living. I hate chaos.

I have so many opportunities living in my own home. I’ve built and developed lots of relationships.

What matters to me?
My collections
Books that I wrote
My cat
My fireplace
Tranquility and calmness.

When life gets so busy and hectic and my problems are weighing me down,
I can sit in my chair, look out my window with my cat in my lap and let my
troubles go by. Having my home is worth it. It makes me feel proud. My
home is a gift.

Listen to what Darla is talking about. Does it sound familiar at all? Doesn’t it sound like
your own home? If so then you are fortunate, sadly many others are not. Why? We
believe this is the result of a myth about living in your own home: it is prohibitively
expensive to provide necessary daily supports for people to live in their own homes,
especially people whose supports are more complex.

Is Congregation Necessary to be Cost Effective?

Total Living Concept (TLC) has supported people to live in homes of their own
throughout South King County (metropolitan Seattle) for over 15 years. At Total Living
Concept, people have a home of their own and only live with people of their choice.
Recently, an opportunity arose to compare the costs of the state contract for the 26 people
supported through TLC with most of the remaining people who received supported living
services through a contract with the State of Washington. In 2006, faced with a budget
emergency, the state agency responsible for supports to people with disabilities sought
information about how people were receiving their supports in communities around the
state. Among other factors, data were gathered by state employees with respect to (a) how
many people receiving state supports made up households, (b) what the daily rate for
those supports was, and (c) what proportion of those people were participating in federal
rent subsidy programs. Supported living agencies in King County reported the data
presented in Table 1.
Table 1
King County Supported Living by Household Size

<table>
<thead>
<tr>
<th>Size</th>
<th>N</th>
<th>Mean Rate</th>
<th>Mean Hours</th>
<th>Voucher</th>
<th>Project</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>265 (31%)</td>
<td>139.67</td>
<td>9.23</td>
<td>63%</td>
<td>7%</td>
</tr>
<tr>
<td>2</td>
<td>135 (16%)</td>
<td>184.91</td>
<td>12.22</td>
<td>12%</td>
<td>40%</td>
</tr>
<tr>
<td>3</td>
<td>246 (29%)</td>
<td>249.39</td>
<td>16.48</td>
<td>37%</td>
<td>3%</td>
</tr>
<tr>
<td>4</td>
<td>206 (24%)</td>
<td>227.36</td>
<td>15.08</td>
<td>15%</td>
<td>38%</td>
</tr>
<tr>
<td>Total</td>
<td>852</td>
<td>200.33</td>
<td>13.25</td>
<td>32%</td>
<td>21%</td>
</tr>
<tr>
<td>TLC</td>
<td>26</td>
<td>247.93</td>
<td>16.38</td>
<td>85%</td>
<td>0%</td>
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</tbody>
</table>

Examination of the data in Table 1 demonstrates that the daily cost rates for people supported by TLC, are comparable (and even slightly lower) to those for people living in households where 3 people with disabilities share a house. The hours of support provided through TLC are almost identical to those of people living in groups of three. The most notable difference is in the proportion of people who participate in the federal rent subsidy program under Housing and Urban Development’s Section 8 program. The proportion of people choosing supports from TLC and concurrently receiving a voucher for rental subsidy is over twice that of other people receiving supported living services in groups of 3. An important point is the option included in the Section 8 program that provides an “extra” bedroom for those people who can demonstrate their need for a roommate in order to rent a house or apartment. Using this option provides an opportunity for overnight support to be provided by a roommate who does so in exchange for a rent-free room. Of course, the choice of who this person is rests entirely with the person supported.

We fully realize these data may have limitations. First, they represent only 26 people compared with 852 and all residing on one, large metropolitan housing market. Generalizations should be made with caution. Second, since we have no data related to the individual characteristics of the 852 people receiving their supports from other agencies with which to compare to people supported by TLC, we cannot rule out

---

1 Mean rate = mean daily rate including support and administrative, Mean hours = mean rate/15.13 (benchmark rate for each hour of support), Voucher = percentage of people with a section 8 rent voucher, Project = percentage of people in a HUD/Section 8 housing project.
individual differences as a source for the favorable daily rate and hours of support comparisons. However, given our local knowledge of supported living and our familiarity with other agencies and the people to whom they provide support we are comfortable that these data are an accurate comparison. Our interpretation and explanation for the comparability of rates in groups versus individual homes lies more in the range of supports provided by TLC and the fact there are advantages inherent in living in a home of one’s own that help keep support costs favorable.

Homemaking 101:
Some Thoughts on How to Stay within a Reasonable Budget

The easiest way to explain how supports are provided to people choosing TLC as their support provider is to think about what people who are called brokers, or case managers do. Until sometime in the mid 90’s case managers in our state engaged in a much wider range of supports designed to connect people with disabilities to a wide array of other programs or assistance. For example, case managers would assist people to apply for other forms of financial assistance (e.g., Section 8 and social security benefits) or locate and enroll in employment programs. Support brokers were initially conceived as people who would connect people to other community supports to supplement or even replace some disability agency funds. Over time the duties of case managers in our state have evolved to focus on eligibility, compliance and documentation. While the staff of TLC does not meet the definition of an “independent” broker, they do work toward locating other, community supports for people with disabilities. For example, staff at TLC:

1. Connect people to financial supports which they, as people of lower incomes, are entitled. Among those are: rent subsidies; roommates to share expenses and supports; lower cost utility, telephone, and internet services; home weatherization; and home remodeling for accessibility.

2. Assist the individual to arrange a plan in the event that emergency support is needed. This is done by recruiting a person (referred to as the local on-site) in close proximity to the individual’s home. The role of the local on-site support is to assist the individual access TLC personnel. A variety of means are used across on-site support arrangements (e.g., electronic devices that sound in the on-site support’s home) for the person to signal that they need TLC staff assistance. On-sites must pass background checks, be trained by TLC and agree to the terms of a TLC contract. The contract includes a stipend much lower than the cost of staff staying overnight. This kind of arrangement is carefully examined for its match with the support requirements of the individual before it is used.

3. Assist the individual to find a preferred location for their home. Our experience is that people choose where to live based on being close to their family, their friends, their school, and/or their job. What those places often represent is an already existing network of support that may result in less reliance on TLC staff. For example, someone who chooses to locate their home near the neighborhood where they grew up will have friends or family member to support them during an activity such as a church social, thus reducing the need for paid staff.

4. Place control of fund allocation in the hands of the individual receiving support. This is accomplished by assisting the individual to develop a plan for the
allocation of funds. For example, one person TLC supports was provided a wheelchair accessible van through the local vocational rehabilitation agency. However, she needed to fund the costs of operating that van. To help her accomplish this, “personal support dollars,” a budget line earmarked for her use was embedded in TLC’s budget. Having control of her money allowed her to tailor support specifically to her needs. In addition to giving her greater freedom it also reduces the demand on TLC to arrange transportation.

While it is difficult to quantify some of the cost savings associated with providing support in this manner Table 2 provides data on 2 areas of notable importance: use of Section 8 roommates; and the use of on-site support. The data in Table 2 were calculated using the costs that would be paid to TLC under the state’s hourly rate for staff coverage as opposed to the costs of using on-site support and roommates.

Table 2
Cost Savings from On-site Supports and Section Housemates

<table>
<thead>
<tr>
<th>Hrs.</th>
<th>On Site</th>
<th>If Staffed</th>
<th>Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>11,256</td>
<td>$38,523</td>
<td>$112,446</td>
<td>$74,474</td>
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</tbody>
</table>

Hrs. Housemates If Staffed Difference

<table>
<thead>
<tr>
<th>Hrs.</th>
<th>Housemates</th>
<th>If Staffed</th>
<th>Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>17,846</td>
<td>0</td>
<td>$287,499</td>
<td>$287,499</td>
</tr>
</tbody>
</table>

Total Difference $361,973
Total Daily Hours Difference 61.55
Mean Daily Hours Difference Per Person 2.37
Additional People at Mean 3.75

Obviously the costs savings are significant. Table 2 indicates the savings to be enough to provide support to almost 4 more people over the costs of staffing these hours. We would note again these supports are never used if anyone is uncomfortable with them or does not believe they adequately provide for a person’s health and safety. Over the past six years no one receiving on-site support has had an emergency requiring the intervention of TLC staff. Staff was only summoned to one home twice, both due to false alarms. Similarly, housemates have rarely needed to call upon TLC for assistance in the over night hours.

Lastly, we would ask you to consider the graphic labeled “The Value of My Own Home.” This graphic summarizes the views of the people supported by TLC, their families, friends, staff and others knowledgeable about community supports. These valued benefits of having one’s own home are more difficult, if not impossible, to quantify but, we think, no less important to consider in valuing a home of one’s own.

Among the benefits that people identify as accruing from living in their own homes as opposed to congregate living include: greater opportunities for inclusion; improved mental, physical and emotional well-being; and choice and control over their home’s
environment. To what extent do we expect these benefits from programs at the state and federal level? Housing seems to be the objective rather than homes. The exchange rate for getting into a "residential service" is typically giving up the ability to make a house into a home. Why would this "trade" seem like a good one? For people with disabilities it is often an all or nothing proposition: live in a congregated group or receive no services at all.

Along with this graphic we would also ask you to consider the experiences of the second author of this article.

I am really excited to be sharing this with you. I want to start by saying it was hard work and determination that got me here. I have been lucky enough to be listened to for many years. I think I can say that I want to always be listened to. I think it’s key. I tried to think of what to say and I keep thinking of peace. I have peace! I have a house in a great location and wonderful people to help me live. I take nothing so seriously as I do my house. I lived in groups for several years and this is much better. I very much want you to understand that I will always be okay as long as I have a home. I find it to be the most important thing I can do for myself. I want to always have what I have right now.

Having a home creates abilities that I would not think of without a good, peaceful place to relax. I think I am super and I have a good life and I want to stress that if I can do it, I think everyone can. I want to see everyone try. I think it’s important to have a place of my own and be able to reflect on my thoughts without chaos. Yes! I take this very seriously. If I had chaos, I couldn’t live. I think I would be a mess! Right now things are wonderful. It’s because I have a peaceful place to be!

Other things open up for me because I can handle them and I always manage to handle them with class. Okay, that’s it, easy for me to say. This has made all the difference with my supports. I couldn’t be so positive if I didn’t have a good home.

Conclusion: Can’t Find My Way Home?

So, what makes a community? People certainly. But also, the fact that they share a common place and are shaped by the experiences within their own homes and the experiences they share with their neighbors. This is the manner by which people develop a sense of belonging with each other.

Most people live in a home of their own. If not, it is typically considered unusual or tragic. Under what conditions are people without disabilities required to live with others not of their choice? Prisoners in correctional facilities; soldiers living in a barracks or on deployment; or members of a religious community where congregate living is required are examples that come to mind. Most assuredly this is not how most of us want to live. We live in homes where we choose the place and have a say over whom, if anyone, occupies that home with us.

Not so for most people with developmental disabilities. We tell ourselves that leaving institutions is a good thing. And it certainly is. But it isn’t enough to just live in a community. Can it even be called living in a community if it lacks opportunity for shared experience with others in that community? Isn’t living in a community about sharing in
the experience of creating a place of your own in the world? Being mutually supportive of each other’s right and need to do so? It’s time to realize that living in the “community” is a great dream we have for everyone. But it cannot come true until the possibility of creating that special place we call home is brought into everyone’s life, particularly for those to whom it has so long been denied.

Darla Emerson is a self advocate and aspiring writer. Bradley Jones is a self advocate and public speaker. Lyle Romer, PhD, Executive Director and Mary Romer, AA, Supported Living Coordinator, both work for Total Living Concept in Kent, WA. For more information about this article, please contact Lyle at lylromer@totallivingconcept.org.

References


Figure Caption

Figure 1.: The value of my own home.
This report examines organizational aspects of agencies working to support people with developmental disabilities in supported living arrangements that provide individualized help to enable individuals to live in homes of their choice. The report is based on meetings and interviews with agency directors and staff throughout the country. Part I looks at struggles in shaping an organizational culture that can provide such support. It identifies various levels of relationships and possible tensions, examines ways of shifting thinking to a more open benefit-focused mindset, and outlines the role of written products. Part II focuses on issues of structure and power in supported living agencies and covers assistance relationships, the team, the management team, the director, important environments, forms of power, occasions of power, negotiating resources from the service system, building effective teams, maintaining balance between the organization as a whole and its teams, setting and maintaining direction, maintaining integrity, and the director's responsibility. Part III describes various ways that organizations develop and relates these to their effectiveness as supportive living agencies. It proposes that new images of organizations fit supported living programs better than views of organizations as machines. (DB)
More Than Just a New Address
Images of Organization for Supported Living Agencies

John O'Brien & Connie Lyle O'Brien

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58 Willows Dr. - Lithonia, GA - 30038-1722
Phone/Fax (404) 987-9785
Reports in the Perspectives on Community Building series discuss issues of concern to those who are working to increase the presence and participation of people with developmental disabilities in the neighborhoods, workplaces, schools, and associations that constitute community life.

These papers are based on visits to innovative human service programs and focus group discussions. Program visits include intensive interviews with program leaders and staff, and usually with some of the people they serve. Discussions include people with different interests and points of view: people with developmental disabilities, family members, people who provide and manage services, people who make policy and manage service systems, and others who work for stronger, more inclusive communities.

Preparation of this report was supported through a subcontract from The Center on Human Policy, Syracuse University for the Research & Training Center on Community Living. The Research & Training Center on Community Living is supported through a cooperative agreement (Number H133B80048) between the National Institute on Disability & Rehabilitation Research (NIDRR) and the University of Minnesota Institute on Community Integration. Members of the Center are encouraged to express their opinions; these do not necessarily represent the official position of NIDRR.
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Introduction

The director of an agency that has moved from operating several group homes to providing supported living described her experience of the change like this.

When we decided to change from group home to supported living, I thought it would be good for the people we serve. At first, I didn’t think much about how our agency would have to change beyond figuring out how to find apartments and getting staff used to dealing with people in different locations. The change has been good, for all of us. But a lot more has had to change about the way we do things than I ever thought. Doing supported living is more than just getting people a new address.

People with developmental disabilities can live well in their own homes if service system and agency managers can implement significant changes in the way people receive the assistance they need. A growing number of innovators identify this change as a shift from residential service to supported living. Supported living means providing people with disabilities the individualized help they need to live successfully in a home of their choice. It contrasts with residential service, which groups people with disabilities in residential facilities for the purpose of training or treating or caring for them. Residential facilities may be large, like institutions or nursing homes, or small, like what some people call “family scale group homes” or “apartment living programs.” Making the shift to supported living involves more than providing a different location or a different type of service. The shift requires organizing and managing systems and agencies in new ways, ways that challenge common mental pictures of how organizations work and how they change.

The discussion and interviews at the base of this report asked people who are experienced in developing and managing supported living agencies to think about this question:

What is different about the way people organize their agency when the agency works to support people in their own homes and in community life instead of working to provide care and treatment in a residential program?

Some new images of organization and agency management emerge from considering their reflections on this question.
This report has three parts:

**PART I** identifies some of the struggles in shaping an organizational culture that offers people with developmental disabilities good support to experience a dignified life in community.

**PART II** focuses on issues of structure and power in supported living agencies.

**PART III** describes the effects of competing ways to understand what organizations are and how they change on the effectiveness of supportive living agencies.

In preparing this report we drew on

- A series of working group meetings and interviews with members of the Washington State Residential Service Guidelines Task Force that took place in March and May of 1991

- Interviews with staff and managers from Training Toward Self Reliance in Sacramento, CA in December 1989 and April 1991


- Interviews with staff and managers of Renaissance House, Tiffin, OH in February 1991


We are grateful for all of these people's hospitality, openness, and thoughtfulness in identifying and discussing difficult and complex issues and we hope we have not distorted or oversimplified their concerns and insights. We also appreciate the comments of our colleagues Jack Pealer, Julie Racino, Mary Romer, and Steve Taylor on a draft of this report. Of course, we remain responsible for its content.
I. New values call for a new organizational culture

Since 1983, the Washington State Division of Developmental Disabilities has supported a statewide learning process designed to build consensus on the desired outcomes of the state's residential services. Important activities in this process include:

- Maintaining the Residential Guidelines Task Force, a committee which includes managers and direct service staff from residential service providers; representatives of People First, a statewide self-advocacy organization many of whose members reside in services; the state ARC, an organization representing the interests of many families with disabled members; the state Developmental Disabilities Planning Council; regional case management staff; and county and state officials with responsibility for the development, coordination and operation of services. The task force acts as a focus for learning about residential services and has debated, drafted, disseminated and revised several statements about service direction and regulation based on comments and criticisms from many people.

The Division of Developmental Disabilities wants people who receive Residential Services to experience these benefits:

- Health and Safety
- Power and Choice
- Personal Value and Positive Recognition By Self and Others
- A Range of Experiences Which Help People Participate in the Physical and Social Life of Their Communities
- Good Relationships with Friends and Relatives
- Competence to Manage Daily Activities and Pursue Personal Goals

These benefits characterize good quality life for all people and people with developmental disabilities should not be deprived of them because they need special services to meet their special needs.

Effective residential service providers learn to offer necessary assistance with housing and daily living in ways that increase people’s experience of these benefits. Since each person has unique preferences for realizing these benefits and makes unique decisions when facing conflicts among them, this learning process will challenge every program’s capacity to offer individualized services. Because current regulations governing residential services focus on different requirements, implementing these requirements may require planned change in the organization of a program’s resources.

- Convening an annual, statewide conference in Ellensburg WA which brings together a large number of service workers, service managers, and people and families who use services to share their experiences and to hear from innovators in community services and leaders in community building from outside the disability field from across North America. This conference provides an annual forum for discussion of progress and problems in understanding and implementing the directions under consideration by the Residential Guidelines Task Force.
• Offering technical assistance to residential service providers which allows them to hire people to assist their agencies. These activities focus on improving agency capacity to train staff and make organizational changes necessary to create the benefits identified as desirable by the Residential Guidelines Task Force. Some technical assistance is offered in workshops and some is in the form of agency consultation.

• Supporting five residential service providers to implement pilot projects under the guidance of the Residential Guidelines Task Force. Pilot agencies engaged in planned organizational change projects in order to test different approaches to creating and measuring the benefits described in the guidelines. Each pilot agency received a small amount of money to free staff time for change activities and to allow agencies to hire consultants of their choice to assist their work. Members of the Residential Guidelines Task Force monitored each pilot project, sponsored an external evaluation of changes resulting from the project, and held retreats to encourage exchange among pilot project participants. Representatives from each project joined the task force.

Greater clarity about the benefits supported living should offer people creates tension with current agency structures and procedures and the way staff jobs are organized. Out of this tension, new ways to organize can grow.

The pages with the lines at the top and bottom [5-13] summarize some of what members of the Residential Guidelines Task Force have learned about organizing to support people in community life by depicting the images of change they shared in two retreats.
Insuring that agencies support people with developmental disabilities to have valued experiences calls for long term personal and organizational learning. The challenge is to continuously clarify what the benefits mean through a process of developing practical ways to support a growing number of people to experience these benefits.

Agency focus on these benefits doesn’t define a model or a set of answers. Awareness of the benefits works like a lens. By discussing the meaning of the benefits, developing ways to approximate measurements of the benefits, and continuously improving the effectiveness of their work, people who provide support learn to see in new ways. They learn to see the person who relies on them for assistance as an individual who belongs in the context of community life. This new way of seeing leads to better understanding of each person, more knowledge of local communities, and a growing understanding of what it takes to support people to take and keep their rightful place. Each time people act on what they see, they refine the lens.

Acting to support valued experiences challenges all of the levels and relationships among participants in the existing system of services. People at each level have to strengthen their ability to participate responsibly in equal relationships and decrease their dependence on top-down controls. Relationships have to become strong enough to allow people to figure out complex issues together.

System Levels
I. Person to person.
II. Staff member to agency
III. Agency to agency
IV. Agency to funders & regulators
People who take the benefits seriously experience three different levels of tensions:

- Each benefit makes an important contribution to the quality of a person's life, but discovering the way to experience each benefit and achieving harmony among them is the project of a lifetime. People make choices that put their safety at risk; close relationships often constrain choices; moving out to participate and exercise new skills can threaten relationships. The more limited people's experiences have been and the less able people are to speak for themselves, the more complex these tensions will be.

- Most stakeholders (from funders to family members) expect the residential system to offer highly specified packages of service to people grouped by disability label, often in special buildings, and almost always in isolation from community life. Boundaries between day, residential, and case management systems are supposed to be clear and distinct. Offering individual support on the basis of people's choices, abilities, and place in the community turns these expectations inside out.

- The culture of most provider agencies expects and reinforces certainty: job descriptions and policies define clear staff roles and responsibilities; professional teams and human rights committees make individual plans that authoritatively guide everyone's behavior in difficult situations; objective inspection guarantees accountability. Learning how to identify and do what it takes to assist individuals calls for willingness to live constructively with ambiguity.

To avoid the discomfort of ambiguity, people retreat into false certainty or leap into abstraction. False certainty leads some people to reject the benefits as "unrealistic." Abstraction lets people avoid what they need to find out about particular situations and specific individuals by debating about hypothetical examples and general questions. Because people live in ambiguous situations, the best way to deal with ambiguity is to stay with it and work to figure out particular situations involving real people.
Service providers who have worked to understand the benefits through action have often discovered that their existing structures and arrangements are shaped wrong: they eclipse the energy that flows from a clear focus on the benefits. Some providers have had to face obvious incompatibilities between group living arrangements and individual benefits; others, in apartment living programs, have had to redefine their jobs from a focus on training people in apartments to supporting people in community settings, roles, and relationships.

Most existing services are based on unequal, hierarchal relationships. Direct service workers, who are themselves at the bottom of the organization in status, salary, and influence over organizational resources spend most time with the people who rely on the agency. They are accountable to those above them to carry out instructions. Often, their relationship with the person they support mirrors their relationship to their agency: they act as if they were in charge of the person they assist and expect the person they assist to be accountable for following the instructions they pass on. Agencies that support valued experiences strive to form and encourage equal relationships between the people who offer assistance and the people who rely on them. A person with a disability has the best chance to experience benefits in an equal relationship with someone who is able to listen and who has influence over the way the support agency uses its resources. Of course, this means that agency administrators have to be willing and able to negotiate with funders and regulators for their own ability to influence the way their agency resources are used.

Many large and small changes in organizational systems and structures will be necessary to align available resources with the kind of staff activities that offer people real benefits. An agency supporting valued experiences needs a management team committed to improving their administrative, organizational, and supervisory skills as they deepen understanding of the benefits.
Implementing services that support valued experiences calls for a new way of defining opportunities, understanding issues, and solving problems. In short, it calls for a new way of thinking together. This new way of thinking begins with a shift of context.

- In typical programs, action supposedly flows from state policy and regulations to local program structure. Regulation and program structure form the context for the relationship between the person assisted and the people who provide assistance. Administrators encourage staff to check their actions for conformity to individual plans, agency policies and procedures, and state regulations. Staff ask supervisors and technical assistants for cookbook approaches to problem solving which will protect them from liability for mistakes.

- To learn to implement the guidelines, administrators and staff shift the context of their work. They aim to make action flow from relationships with the people they assist. They work to merit people's trust by listening carefully and responding truthfully and consistently to what they hear. Better understanding of the person's interests and needs grows from relationships and focuses problem solving. Administrators encourage staff to think and act creatively to develop opportunities and overcome obstacles. Creative problem solving includes figuring out ways to deal with regulations and take account of liability concerns. Staff ask administrators and technical assistants to join them in improving their problem solving.

To see the contrast between these two contexts, think about the practical difference between these two questions. Staff who answer the compliance question will see, act and learn differently from staff who answer the relationship question.
Many, many repetitions of this simple learning process move people and agencies along the long wave of change toward greater capacity to offer people benefits. Working inside the boundaries defined by the guidelines, staff join the people they assist and other community members to learn by moving from action to reflection and back to action. This process means regularly taking time out from action to stop, to look at what's working and what's not, to think about what lessons the current situation offers, and to plan for the next steps. Effective administrators encourage this process both around individuals and for the program as a whole.

Most often reflection will be informal, a part of everyday work. More structured forms, like personal futures planning or retreats, offer opportunities to reflect on bigger chunks of experience.

Offering services that support valued experiences means building an organizational culture that will sustain effective relationships and continuous learning. People who provide direct assistance build up an effective culture when they act more creatively in their everyday work. People in administrative roles build up an effective culture when they model the necessary qualities in their own lives and in interaction with the people and programs they supervise. The more funders and regulators understand and encourage the kinds of behavior that allows effective problem solving, the less they will inhibit the development of effective organizational cultures in the agencies they depend on to serve people.

Administrators concerned with keeping learning alive will keep raising questions: "Are our values alive?" "Is our work satisfying?" "Have we mindlessly fallen into routine?" Effective administrators at every level of the system will make time to gather people together to deepen their understanding of the values and organizational qualities necessary to offer people real benefits. Budgets, job descriptions, supervision and staff development processes will reflect growing understanding of the qualities that distinguish an effective organizational culture.

In an organizational culture that supports valued experiences

✓ Commitment to vision is ok.
✓ Ambiguity is ok.
✓ Questions are ok.
✓ Trying new ways to look at and do things is ok.
✓ Looking at yourself and your own life is ok.
✓ Asking for help is ok.
✓ Personal involvement with people you assist is ok.
✓ Working outside usual program boundaries & routines is ok.
✓ Reaching out to involve new people in our work is ok.
✓ Negotiating for what you believe people really want & need is ok.
✓ Taking time to reflect & to invest in learning new things is ok.
An important aspect of change is developing a new mindset: a different way to think about and evaluate situations. A mindset that focuses staff attention only on carrying out service procedures locks staff and the people they support into a narrow range of options. People experienced in implementing the guidelines call this "being in the box." What’s needed is a mindset that "opens the box" and focuses attention on people in the context of their communities.

Staff who increase the benefits that people with disabilities experience don’t just act differently from staff who deny or miss opportunities for greater benefits. They notice different things and think differently about them. Their work requires them to be able to...

- Think on the spot
- Negotiate shared understanding of situations among people who often have conflicting views
- Try things and test whether or not they improve the benefits people experience

Changing your mindset isn’t as easy as changing your shirt. It involves letting go of the current boundaries that describe jobs and define priorities and re-defining boundaries that include more attention to differences in individual interests and circumstances, more attention to community opportunities, and more attention to negotiating better relationships.

Experienced staff say that this change is like learning a new language. There is a movement away from the familiar that feels uncomfortable because it involves loss of fluency and self-consciousness about choice of words and frequent errors.

As new patterns emerge, so do new opportunities for deepening understanding of people and their communities.
Three kinds of actions help people manage the shift to a more open, benefit focused mindset.

I. Bring together people who care about a person and other people with responsibilities to that person and strengthen their relationship with the person and the bonds between them. The purpose: to clarify and increase commitment to the person and to find common direction in varied ideas about the person.

II. Increase awareness of the ways current boundaries and rules get in the way of taking responsible action and work to re-negotiate these constraints. Crisis situations - situations that hold the threat of chaos - offer excellent opportunities to strengthen a new mindset. Acting constructively in crisis means moving into chaotic situations rather than trying to escape them. The challenge is to be part of an emotionally charged situation and think about how to redefine the situation so that the people in it can act in ways that will increase benefits. The process is simple:

- Notice that we are acting and thinking as if we were "in the box."
- Identify some of the specific ways we are acting and thinking that either makes the crisis worse or frustrates the accomplishment of some benefits for the people involved
- Try out new ways to think about the situation and new ways to act.
- Invite people from outside our local chaos to help us see what is happening and what options we have

III. Learn to discover and communicate visions that...

- Clarify answers to the basic question that defines the relationship between a person and those who provide service: "Who is this person and who are we in this person's life?"
- Make it obvious that the person and those who care about the person and the people who provide service are in partnership to improve life together. "What do we want to be doing together in a better future?"
- Energize the hard work of changing our mindset by working to overcome barriers to change and acting responsibly in crisis situations.
Leaders of agencies that have worked to support valued experiences say that they have had to invest time in building a shared understanding of the benefits. People need an organized process to clarify their understanding of the benefits, debate their importance, and define ways to act that will increase the benefits people experience. This process of change can be organized around designing and testing ways to measure changes in the level of benefits people experience and by modifying policies and defining new procedures. But the written results of undertaking these tasks are a better record of where the agency has been than they are a recipe for producing a better future. As one person said, "The investment in setting up new measures was well spent. It helped us make some important transitions. But now we don't make as much use of them as we did. We still take the measures, but now they are less important because we have learned new ways to talk and work with the people we support."

...but written products don't create organizational learning

This discovery has important implications for the process of helping more agencies to implement the guidelines. Bureaucratic thinking would lead to the conclusion that the necessary changes can be effectively translated from innovating agencies to new implementors in words. From this point of view, a new agency simply adopts policies, procedures, and measurement and planning systems from an effective pilot. Training and technical assistance focus on transmitting the products from pilot sites.

Experienced implementors of efforts to support valued experiences fear that reliance on words alone as the translator will create what has become their nightmare: the words will change but people's experiences won't. Even worse, more subtle measurements could lead to even greater control of people's daily lives.
Dissemination of what the pilot projects have learned calls for the development of better translators of the pilot project's experience. Better translators get new implementors involved in their own pattern of learning through reflection on action. New implementors can't be consumers of products developed by the pilots or passive recipients of teaching and technical assistance; they have to become producers of change in their own communities. New implementors can't hold the people who assist them responsible for telling them sure-fire solutions to the problems that come along with implementing support for valued experiences; they have to take responsibility for learning for themselves with the guidance and support of people who are more experienced.

Agencies that want to begin to support valued experiences can accelerate their learning by...

- Listening carefully to descriptions of the processes other agencies have followed and thoughtfully designing their own change process based on what they have learned.

- Studying the products of other agencies' change efforts and using them as stepping stones in the development of their own policies, procedures, and ways to gather information about people's experiences.

- Getting involved in active learning experiences that give people a chance to try out some of the actions that can shape a new mindset. Some pilot agencies have found the Framework for Accomplishment* workshop helpful for this kind of try-out.

*Framework for Accomplishment is a process for identifying the capacities a service program needs to develop in order to assist people to move toward a desirable personal future. One support to change in Washington state has been a series of intensive workshops which give people experience with using the Framework for Accomplishment process.
II. Supported living calls for new structures & new uses of power

Effective supported living agencies are well structured and powerfully led, but they look and feel different from typical human service agencies. The structures and the forms of power that shape and guide them differ from the bureaucratic patterns of organization and management common in residential service agencies because the nature of a supported living agency's work differs fundamentally from the work of a residential service agency.

Reasonable people might wonder whether it makes sense to think about supported living agencies at all. A small and slowly growing number of people with severe disabilities do not rely on agencies to provide the support they need, nor do they depend completely on the help of family members. They, or their families and friends, raise and manage necessary funds and organize a support system for themselves. They resolve the question of structure without agency intervention. **

The notion of replacing agency-client relationships with consumer control in a personal assistance marketplace has many appealing features, especially to people worn out by the inflexible, costly clumsiness of bureaucratic systems. However, most people with developmental disabilities who live outside their parent's home or a residential facility now depend on a supported living agency because current public policy severely restricts people's option to control their share of available funds. And even when people with disabilities gain full control of available cash — as we believe they should — it is reasonable to assume that some people will probably choose the convenience of purchasing services from a supported living agency over the investment of time required to self-manage a personal support system.

Whether a supported living agency is legally organized as a non-profit corporation or as a cooperative owned by those who use its services; whether board and staff members have disabilities or not, the way the agency resolves problems of structure and power determines the quality of life for those who rely on it for support.

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**This section is based on a working group discussion with Gail Jacob, Kathy Bartholomew Lorimer, Beth Mount, and Steven Taylor which centered many of the findings from our field visits to supported living agencies. We also acknowledge Jeff Taylor and Aaron Lemle and Fiona Farrel for their contributions to our working group.

Assistive relationships

The fundamental structure at the foundation of a supported living agency is a set of relationships between a number of people with developmental disabilities and their assistants. Each person will have a unique and changing mix of personal assistance based on the person's preference and need as the person's preferences and needs emerge in the relationship.

- Some assistance involves instrumental matters such as getting dressed, eating, communicating, going to the toilet, keeping house, shopping, getting to appointments and activities, and managing money. This help may be from a person who lives-in with the person with a disability or, more commonly, from a person who comes in to help on schedule and as needed. Many people will receive assistance from more than one person and some people will have additional helping relationships with tutors, or counsellors, or communication or physical or occupational therapists. Sometimes, instrumental assistance will involve helping the person to develop or improve their skills; often, the assistant will perform tasks that the person cannot efficiently do alone.

- Some assistance involves helping a person to plan and coordinate their activities and their come-in and live-in help. This help may involve determining the person's preferences and needs about type and location of housing; selection of roommates if the person wants them; transportation arrangements; finding and scheduling activities that offer the person opportunities to pursue personally interesting goals; hiring, training, scheduling, supervising, and firing assistants; and personal problem solving. For many people with developmental disabilities, this role will be like that of an executive assistant: taking responsibility for carrying out the tasks the person with a disability delegates in the way the person prefers. For a few people with substantial cognitive disabilities the assistant will be much more active in interpreting the person's preferences based on their involvement with and observation of the person. For some people the assistant's role will be complex because the person will be able to assert clear preferences in some situations and will find other situations extremely challenging.

The diagram above shows a three person relationship, separating instrumental assistance from assistance with planning and coordination and assigning some supervisory responsibility to the planning.
assistant. In practice, it is very common for the person who provides planning assistance to also offer help with everyday tasks, and many people will have only one helper who combines both functions. Some people will have more than one live-in or come-in assistant. Whatever the configuration, its emergence from the particular situation of the person with a disability involved is the hallmark of supported living.

Being a good assistant challenges each support worker's capacity to sustain a close working relationship. In the context of this relationship, depending on individual circumstances, support workers may be called on to...

...identify and help the person to respond to potential opportunities and potential dangers in their situation

...facilitate people's problem solving efforts

...help people interpret and make sense of matters as diverse as apartment security deposits, or the results of medical tests or the possible reasons for a neighbor's hostility

...advise people in matters of importance to them

...represent people's interests when they have conflicts with landlords, bus drivers, police officers, service providers, physicians, income maintenance workers and others

...assist people in identifying their strengths and interests and the ways they can pursue them.

Maintaining any good working relationship is difficult. Assistive relationships can be particularly complex because...

...sometimes the support worker has multiple responsibilities: 1) to follow the instructions and respect the preferences of the person with a disability; 2) to help the person discover what their preferences are; 3) to interpret a person's preferences when severe cognitive disability makes the person's preferences uncertain; and 4) to protect a person who is vulnerable

...the person with a disability depends on the support worker for vital assistance and so may try to please the support worker rather than asserting and negotiating their own needs and preferences because they feel vulnerable to the support worker's goodwill and threatened by the possibility of the support worker's disapproval

...the person with a disability may have poor supervision skills and poor negotiating skills so that the support worker feels mistreated and frustrated
...support workers share, often unthinkingly, in strong cultural prejudices that can easily lead them to treat people with disabilities as less valuable and less capable than themselves.

...the disabled person’s past experience of services may offer them little confidence to trust the support worker: the person with a disability may have been abused or ignored by support workers, or may have had repeated experience of losing good support workers to high turnover.

...in many ways people with disabilities live in a hostile environment — many of the people they meet will devalue them, a few will openly reject them because of their disability, and a few will exploit their vulnerability; this means that the support worker has to assist a person to assess and deal with risks without either being naively optimistic or unrealistically pessimistic about other citizen’s responses.

...support workers have to stay clear about the ways in which their personal preferences and values may differ from those of the person they support and keep re-creating ways to avoid imposing on the person they assist without compromising their integrity.

Support workers’ jobs are complex because they are closely involved with socially devalued people who need their daily help with important matters in their lives. This diagram illustrates just one of these complexities by suggesting that individual freedom is, among other things, a matter of both choice and personal involvement or engagement. No one is free without choice and no one is free unless what they decide matters to some others.

Policy and practice have routinely denied people with disabilities choice, thus trapping them in abusive or overprotective situations. Supported living agencies properly commit their workers to actively promote people’s choices. But policy and practice have also routinely discouraged committed, personal engagement with people with disabilities. Often this has extended to isolating people by breaking people’s relationships with their families and disrupting potential friendships among people with disabilities. Disengagement creates an abusive situation when people are also denied choice and it sets up a potentially neglectful situation when people can decide for themselves but no one is personally engaged with them. People who are isolated face a much increased risk of being exploited. Support staff who stand back and let isolated people sink into difficult or
dangerous situations without comment or effort because "our agency gives people their right to choose" or "we believe in friendship and choice and she picked an abusive friend" are simply neglectful. Support staff who work to strengthen their relationship by identifying and attempting to negotiating their differences with a person's choice may contribute to increasing the person's freedom, but the costs of such increased engagement often includes confusion, emotional conflict with the person, self-questioning, and failing to influence the person's choice.

The team*

Membership in an effective team helps support workers to be better participants in their assistive relationships. The team offers the support worker a place to figure out what is happening in complex situations. It provides colleagues who can offer empathy, suggestions, and resources while they pose questions and challenge apparently narrow or prejudiced perceptions or actions. An effective team serves as a focus for personal and organizational learning as team members reflect on their work and plan ways to improve their effectiveness.

The team provides a human-scale link between the agency as a whole and the people the agency supports. At the scale of a team, people can get to know one another well enough to establish personal trust with one another and to identify ways that they can help one another both one to one and as a group. Team members can, in time, come to know the people with disabilities the other members of the team support and thus provide informed back-up from a known person when the support worker a person usually relies on is unavailable. Teams can self-manage the details of scheduling and much of the agency's day to day problem solving. Team members can identify necessary agency or system changes based on their knowledge of particular people's lives and carefully evaluate the impact of agency level decisions on the lives of the people who rely on them.

An effective team leader collaborates with team members to develop, renew, and deepen commitment to the values and direction the supported living agency stands for. Through individual coaching and group leadership, the team leader collaborates with members to improve each member's ability to realize their commitments in everyday relationships with the people they support. The team leader serves as an active link between the decisions affecting the whole supported living agency and the work of the team. This involves representing the
team to the whole agency and the agency to the team. The all too understandable human desire to use groups as a place to flee from difficult issues into blaming or wishful thinking or unproductive fights makes effective team leadership a demanding role.

Some people raise an important question, "If staff need the support of a team, what independent opportunities do people with disabilities have to figure out what is going on and how things should be better?" When people with developmental disabilities have friends and involved family members, they have the chance to develop an independent perspective on the assistance they receive. When previous services have isolated people and discouraged them from reaching out to others, they have fewer options. Some people have found independent support among other people with disabilities in an advocacy group. A few people have formed relationships through citizen advocacy programs. A few people have formed circles of support, usually with outside help. A community that lacks such independent, organized responses leaves those people who need help to overcome isolation in a dilemma: they rely on support workers to assist them to form relationships independent of the support agency. Collaboration between people with disabilities and their support workers to overcome isolation is one of the most exciting and confusing areas of work in supported living.

The management team

The management team orchestrates the whole agency's learning about what its chosen values and direction mean and how best to realize them. The management team structures opportunities for people to invest their talents in developing the agency while they influence one another's appreciation of the agency's commitments. Some of their opportunities come in the form of training, but most arise from the work of managing the agency. Working groups take responsibility for such important tasks as evaluating agency performance, developing long range strategies and plans for management and staff approval, designing necessary processes, policies, and procedures, and developing the agency's position with outside resources such as funders, regulators, housing associations, or community development groups. To bring together different talents and points of view, working groups purposefully include people with developmental disabilities, support workers, management team members, agency board members, and other advisers.
The management team assists the work of teams in two ways. First, it coordinates the daily work of the agency in areas where teams may interfere with one another's work due to common dependence on the same resources, such as secretarial services or housing resources. Second, it provides team leaders with the opportunity to develop one another's abilities by offering support in understanding their team's work and challenging and expanding one another's ideas and skills.

The agency director leads the management team and serves as the management team's primary link to the agency board.

The director

Most of the operational management of a supported living agency must happen where people have the information necessary to make operational decisions. The staff who provide planning and coordinating assistance need the judgement, problem solving, and negotiation skills to deal with most plans and problems in collaboration with the person they assist. Of course, placing responsibility for most decisions with direct service staff and the people they support doesn't require them to act alone. Indeed one of their basic skills is knowing when and where to go for help. Teams need the level of trust in one another, the level of commitment to the agency's direction and values, and the group problem solving skills to serve as the main source of learning, support, and coordination for support workers. A variety of workgroups, organized by the management team and the board, need the information and the skill to plan, evaluate, and design policies and procedures.

The director stays aware of the agency as a whole and exercises responsibility for maintaining focus on the agency's values and direction. Awareness of the agency as a whole calls for the director's personal involvement with assistive relationships and team learning. This represents one of the effective limits on the size of a supported living agency. A supported living agency risks being undermanaged when the number of people it assists plus the number of staff becomes too large for the director to maintain personal contact. Responsibility for maintaining direction requires the director to carefully attend to the selection and development of team leaders and support staff and to the composition and preparation of working groups. The director needs more than the authority of position. The director needs the authority that comes from personal knowledge of people's situations and personal commitment to contributing to good solutions when difficult problems threaten to compromise the agency's direction and values.
Important environments

Two different environments provide the resources a supported living agency needs to do its work. Because neither service system nor community are accustomed to supporting people with severe disabilities in their own homes, an agency can't passively adapt to what its environments expect of it. That would push all but the most determined and capable people with disabilities into residential facilities. An effective agency works strategically to shape the service system and the community that contain it.

The service system. In most current instances, the service system provides the money to pay support workers and their managers and coordinates the supported living agency's work with other service providers (such as supported employment or day service providers). The service system typically coordinates both at the personal level, through some form of case management, and at the interagency level, through plans and contracts. The service environment can produce different kinds of conflicts; for example:

- Restrictions on the expenditure of available funds often limits the supported living agency's flexibility in matching individual needs and preferences with available resources. These restrictions increase the transaction cost of providing services in at least two ways. 1) They impose forms of meetings and paperwork which are unnecessary to support particular individuals and which effectively move decision making power away from the person and those who assist for no reason other than to satisfy funding requirements. 2) Gaining waivers, permissions, and developing work-arounds in order to do what seems necessary absorb substantial time. Widespread system dependence on medicaid funds, which were intended to pay for sickness care, compounds this problem.

- Most service systems simultaneously operate different types of services with incompatible assumptions about people with disabilities. Many people who live in and control their own homes with support spend their days in mindless, segregated activities designed to treat and cure or "habilitate" their disabilities. This creates conflicting and confusing experiences for the person. Although the staff of differing agencies work within the same service system, they think about and do their work in different worlds. These fundamental differences in perception and relationship make conflicts across agencies hard to negotiate and greatly reduce the effectiveness of inter-agency coordination.
• Most current systems are built on the hierarchal assumption that people who provide direct service should be less competent and lower paid than the professionals who write plans. For examples, most systems assume that, because of their position, case managers have greater knowledge and far superior judgement about what makes sense for a person they meet formally and occasionally than the support workers who spend substantial time with a person every day. This leads service systems to the low expectations of direct service staff that result in underpaying and undersupervising the people in the best position to learn about and act for the person. It also creates incentives for agency growth because larger agencies can pay more people as managers or specialists.

Failures to make these conflicts into opportunities for small steps toward reshaping the service system impose their consequences on people with disabilities. Failure to succeed in particular attempts to change the service system can deepen support staff’s understanding of the situation of people with disabilities and commitment to ally with them in making systemic changes that will improve everyone’s life.

The community. Communities provide people with disabilities with places to live and work and learn, goods and services to buy, activities and associations to join, and people to make into friends.

Though some community members purposely exploit or act openly hostile to people with developmental disabilities, most discrimination and exclusion arises thoughtlessly from ignorance. Developers see no way and no reason to insure that they build accessible housing. Housing advocates create cooperatives and other new forms of housing on the mistaken assumption that people with developmental disabilities live happily in residential facilities. Landlords and neighbors and shopkeepers and dentists and pastors and police officers worry about unusual demands on their abilities and tolerance or unusual threats to their property, prosperity, and safety. Leaders of associations and activities more often see people with disabilities as a potential project than as a source of interested participants and members.

Supported living agencies most powerfully influence community environments when they assist individual people with developmental disabilities to establish themselves in homes of their own and support them to develop community connections that allow them to discover and pursue their personal interests. Agencies can also support and challenge the people and organizations responsible for housing and
improving the quality of neighborhood life to include people with developmental disabilities in their efforts, their memberships, and their agendas.

The supported living agency links bureaucratically to the service system. Most of the visible work of effectively positioning the agency in the service system gets done in formal meetings and written plans, budgets, reports, and justifications. To deal with the service system, the supported living agency has to be able to look and act like a formal organization—the triangles in the diagram. The director or the director's official delegates deals with agency matters. Staff with professional titles represent the agency in multi-agency individual planning sessions. Budget revisions and reports are filed on the correct forms on time. Agencies only violate these expectations with a purpose, otherwise the service system will be unable to hear the agency's communication. The less visible work necessary to keep bureaucracy from extinguishing purpose depends on agency leaders' ability to sustain good personal relationships with people who manage other parts of the system. These relationships allow the director to build trust and credibility and to make person to person requests for involvement in work on system changes.

The supported living agency links to the community in multiple, informal ways. Most of the work of effectively positioning the agency in the community gets done on the basis of personal connections. Who a person knows and what a person is willing to do are more important than a person's title in many important areas of community action. Most contacts are casual and paperwork is infrequent. To deal with the community, the supported living agency has to act like a source of community action—the circles in the diagram. The agency as an agency very seldom takes an explicit position. Most actions are individual because they arise from individual interests. Support workers assist the people they support to satisfy property owner's concerns about signing a lease or to investigate the possibilities for membership in a community group of interest or to prepare a covered dish for a neighborhood party or to negotiate an appropriate restitution for an offense with the local courts. Agency staff and interested people with developmental disabilities join a local housing action group to align their energy with the efforts of other citizens.

Building the capacity to assume two different shapes to influence two different environments organizes a good deal of a supported living agency staff's learning. Different environments require shifts of mindset as well as calling for different clothing.
Power

Forms of power

Leaders of successful supported living agencies identify the use of power as one of the most important and difficult issues in their work. Several of them find this way of distinguishing between three different types of power helpful in their work:

• **Power-over** other people arises from the ability and willingness to make decisions for others and to enforce their compliance by authoritative control of rewards and punishments. Typical systems and agencies embody the assumption that people higher in a hierarchy will exercise power-over the people beneath them. Professionals and staff unquestioningly expect that people with disabilities will do what they are told by those authorized to plan for them and see those who do not comply as further and more deeply disabled. Power-over others is the most common and familiar form of power. People expect its use, feel uncomfortable at its absence, fear the uncertain consequences of denying it, and easily fall back upon it in times of stress. “Real politicians” and “real managers” and “real organizers” rise and fall on their ability to manipulate power-over. But power-over others poisons the relationships necessary to support people with disabilities to take their rightful place in community life. This appears true even in structures that attempt change by swapping the order in a hierarchy so that the people with disabilities assume power over their helpers.

• **Power-with** other people arises from people’s ability and willingness to listen to and be influenced by another’s perceptions and suggestions and to offer their perceptions and suggestions in turn. Power-with requires the kind of respect that grows with a willingness to be personally involved with one another and to share by choice in a common project that will shape and shift patterns of relationships among people. Differences provide information and the occasion to clarify and strengthen relationships by negotiating creatively. Because power-with depends upon and reinforces cooperation, its exercise depends on people’s mutual restraint and willingness to learn from their experience together. Not all exchanges of influence have positive motives or good consequences, so people need to assume responsibility for questioning and testing the fruits of their collaboration. Power-with defines a strong foundation for the kinds of relationships necessary to support people with disabilities in community life.

• Power-from-within arises from a person's willingness and ability to discover and creatively express the abilities and concerns that they find spiritually meaningful. In civic life and in the world of work power-from-within brings people beyond seeking a role to finding a vocation, a calling. Power-from-within gives a person courage to act when important values are threatened, even if the short-term prospects for success are poor. Several leaders in supported living identify power-from-within as the source of their own ability to overcome their fears and doubts in order to create and protect innovations in difficult circumstances. Because power-from-within expresses a person's deepest beliefs, conflicts can be painful and very difficult to resolve; so many people learn not to share their convictions. People acting on the basis of power-from-within need to exercise personal discipline to sharpen their discernment of what ultimately matters to them and to strengthen their abilities to creatively express what matters to them in everyday life with other people.

Power-with and power-from-within have particular relevance for supported living agencies. Assistive relationships cannot be based on the coercion and fear that come with the exercise of power-over. Support develops on the basis of mutual influence through the support worker's listening and responding to the person with a developmental disability and, in turn, offering the person information, suggestions, guidance and identifying and negotiating differences. Even when there is a definite element of control in the relationship—as when a person has been declared incompetent to make money decisions or when a court makes some form of supervision a condition of release from jail—power-with provides the only constructive context for a support relationship. Either person's use of power-over marks trouble in an assistive relationship that can only be repaired by moving to the ground of power-with. Team relationships cannot be based on coercion and fear. Learning and mutual support require trust and the ability to identify and negotiate differences.

Community relationships cannot be based on coercion and fear. The supported living agency strengthens necessary community relationships by looking for common ground and supporting people with disabilities to make clear requests for inclusion, assistance, or adaptation. Even in the relatively few instances when these requests are backed by enforceable rights, outcomes depend more on creative negotiation and joint problem solving than on giving orders. As anyone who has lived with many attempts to do even simple things like make public build-
ings physically accessible will know, this is because there are so many non-functional ways that even well meaning people can give the appearance of compliance with rules. Assertion of rights gains most ground when it leads people to establish power-with relationships.

Although the context is hierarchal, relationships within the service system cannot be based completely on power-over because the supported living agency is low down in the hierarchy. Because of its position, the agency is expected to take and implement instructions from system managers and multi-disciplinary teams rather than to be a source of action. By establishing power-with relationships in the network of people who manage the service system, supported living leaders multiply their ability to respond to the individual preferences and needs of the people with disabilities their agency supports.

Power-from-within gives the people involved with supported living agencies the energy and courage to stand up to unjust situations, to continue to face and learn from difficult problems day after day, and to find meaning in their lives despite slow progress or failure. Many effective supportive living workers say that they are led and sustained by some people with disabilities they know whose power-from-within is very strong for those who take care to notice and listen to them.

Occasions of power

Assistive relationships form the daily testing ground for power-with and power-from-within. Each relationship includes many moments of truth in which people will either struggle for collaboration or fall back into coercion or withdrawal. Whether assistive relationships grow stronger from these tests depends partly on the people in the particular relationship and partly on the way the supported living agency develops as an organization.

Five recurring organizational issues test and strengthen the use of power in a supported living agency. They are: negotiating necessary resources; building effective teams; keeping balance between the work of the whole organization and the work of its teams; setting and maintaining direction; and, maintaining the agency's integrity.

Together, these issues provide the agency with chances to build up alternatives to power-over. Each issue offers the opportunity to shape stronger collaborative relationships and deepen understanding of the links between supported living work and what its participants find personally meaningful. The way an agency manages these issues determines the amount of energy it can focus on realizing its values.
more practiced people become in organizing their efforts through the exercise of power-with and power-from-within the less organizational relationships will be dominated by power-over.

Any member of a supported living organization can constructively exercise power in each of these situations. Power-with grows when people intentionally draw and re-draw boundaries by moving toward some relationships and away from others. People strengthen the use of power-with in the agency when they...

...bring people together to focus on a common project, especially when this brings previously uninvolved people into the project

...encourage people to say clearly how they see and understand a situation and what they want from it

...inquire about the position of people who disagree or are unwilling to become involved in order to find out what it would take to gain the person's cooperation

...practice creative search for mutually beneficial actions

...advocate for suggestions that structure shared action

...cooperate with other's projects

...question limiting assumptions by inquiring why a desirable action appears impossible

...figure out ways to evaluate and learn from the effects of their actions

People strengthen the exercise of power-from-within in the agency when they...

...invest time in strengthening and clarifying their awareness of what is personally meaningful to them

...look for ways that the agency's work offers chances to express what is most important to them, especially in frightening or confusing or discouraging situations

...speak clearly and strongly about their sense of what matters to them as valuable and fundamental, especially when their agency's behavior seems to be negative or out of control

...listen respectfully and thoughtfully when others speak of what matters most to them
Negotiating resources from the service system

Under current policies, supportive living agencies need to establish a good supply of six resources from some part or other of the human service system:

- **Permission to serve people.** Most service systems control eligibility, set service priorities, take the authority to decide or at least approve who an agency can serve, and control access to people with disabilities—especially those people with disabilities who are inmates of residential facilities.

- **Money to support people,** and sometimes money to subsidize people’s living expenses. Most service systems allocate funds for services and money for living expenses above disability benefits to agencies rather than to people.

- **Legitimacy.** Most service systems take the authority to license or approve service providers and most make such approval a condition of continuing operation.

- **Flexibility.** Inability to respond to changing individual needs and preferences makes supportive living impossible. Increasingly specific and detailed regulation and prescription of the details of agency relationships and behavior serves apparent rationality in public administration even as it destroys agency and system effectiveness. Supportive living agencies live or die on their ability to develop problem-solving relationships with service system managers who use instruments like waivers, new categories of program description and regulations, pilot projects, and innovation funds to create flexibility.

- **Knowledgeable and credible advisors on how the system works.**

- **Information and influence on important issues.** Service systems face uncertain pressures and the ways they choose to respond will matter a great deal to the capacity for supported living. Service system managers may choose to listen more closely and be guided more by supportive living providers than the size of their agencies or their apparent importance would suggest.

Two related strategic issues commonly arise in relationship to service systems. One poses the question of the scale and rate of growth of the agency. The other poses a trade-off between flexibility and amount of available funds.

Service systems have a legitimate interest in offering good services to growing numbers of people. Successful supported living agencies provide an attractive service and are often uncommonly well managed.
(even if the management style and the organization's structure seems odd). So service system managers are likely to press a successful supportive living agency to grow larger and to grow faster. Sometimes this comes as an explicit proposal, "We want you to double in size in the next three years." or "Another provider has lost their license; will you take over their agency and make it like yours?" Sometimes it comes implicitly in individual requests that accumulate to a similar outcome, "Won't you just find room for this one person who really needs you?" Supported living agency management has to maintain control of how large they become and how fast they grow. The difficulty of doing this can be compounded when board members or staff see requests for growth as a clear sign of success and uncritically conclude that the ability to offer good support to a small number is a clear sign of ability to offer the same quality to as many deserving people as the market will bear. Experience suggests caution: agencies that are well managed when small often become uncontrolled when scale or rate of growth turns personal leadership into distant management. Growth will inevitably demand substantial leadership ability and time and will almost certainly lead to at least a short term decline in the quality of support available. At least an agency that decides to grow needs to budget time and resources to learn how to grow bigger.

Money for services is scarce and many service systems predict that it will grow scarcer. This leads system managers to search for funds that have the advantage of availability and the disadvantage of bringing requirements that generate new levels of detail complexity for their system. Supportive living agencies that want to sustain good assistive relationships by being able to offer support workers decent wages and benefits may be offered a deal that allows them a higher rate of reimbursement in return for much more intrusive and inflexible regulations. Supportive living agencies that have carefully made a strategic decision to grow may well be offered the same deal. Flexibility is costly to achieve. Once achieved it is difficult to maintain and easy to lose. Trade-offs between increased money and decreased flexibility need sober evaluation and time for people to explore and align with whatever position an agency finally takes.
Building effective teams

Everyone in the agency contributes to team effectiveness. The agency strongly influences team effectiveness through its personnel and staff development activities. Hiring team members and identifying team leaders are the most important operational decisions the agency makes. Creating ways to develop competence and leadership in team members and team leaders are the most important operational investments the agency makes.

Common assumptions that shape service systems can constrain effectiveness in hiring and developing people. Though the supportive living agencies we have studied have relatively low turn over, most systems assume that the people who offer direct service will do so for very short periods. This assumption makes investments in developing people look like a waste of time and money. So systems generate a vicious circle of underinvestment and adjustment to built in incompetence.

Every team faces two predictable stresses that have agency wide impact: Making decisions in situations where people's safety is threatened, and complying with requirements necessary to agency survival but irrelevant to people's sense of what matters in their work. It's important for the agency to systematically support teams in each of these areas.

Support workers occasionally have to make decisions where a person's safety or health or continued freedom to live in the community is at stake. The agency needs to support its workers in these situations by insuring that they identify these situations; that they recognize these situations as occasions to get help; and that they have a well organized process for thinking through the situation with others and in terms of the agency's values. The agency owes the people it supports and its support workers a framework for making these difficult decisions that is publicly and widely debated, endorsed by the agency board, and regularly reviewed and revised. This framework can't be in the form of simple instructions in the form, "If this... then do exactly this." So people need personal and team support to understand, apply, and learn from it. The issue of response to real threat to health or safety can never be finally resolved. The agency as a whole, like each assistive relationship where such threats arise, has to keep balance in a situation that can easily fall into neglect or overprotection.
As long as a supportive living agency has to function part time as a bureaucracy, support workers will have to meet requirements that have no clear relationship to what matters to them in their jobs. The agency can support teams to deal with this in at least four ways: 1) minimize the agency’s reliance on intrusive funding sources and provide staff with opportunities to explore and debate the implications of the trade-offs the agency makes (“We’ll be able to serve five more people and raise your pay. But these are the requirements you will have to take responsibility for meeting…”); 2) continuously look for ways to decrease the cost of compliance, probably under the coordination of a working group composed of people who enjoy looking for ways to simplify and streamline routine work; 3) regularly review the actual costs of compliance with regulations and actively negotiate with the service system for release from damaging requirements; and, 4) recognize support staff who find ways to comply with requirements without compromising the quality of the assistance they provide.

Keeping balance between the whole organization and its teams

Teams carry most of the day to day responsibility for supporting assistive relationships and an effective team will be a cohesive group. This has advantages for making good decisions and promoting learning. But team closeness can become a screen for moving away from the agency’s values and direction or even a cover for poor performance of support work. Strong teams could mean a weak agency if there are not explicit investments in maintaining a balance between teams and the agency as a whole.

To manage this issue well the agency needs to adopt and apply the principle that any decision that can effectively be made by a person with a disability or those close to the person should be. No decision will be made at a point in the organization farther from the person with a disability than necessary. This means that any requirements for uniformity across teams need careful discussion and regular review.

Team leaders play an important role in maintaining balance. If they work actively to link the management team with the team they lead, they will help each group understand the whole organization better. Being an active link is more stressful than simply identifying with one group or the other. It’s easier on the team leader to define the job as getting what their team needs from “the management” or telling “them” what “we” the management team have decided “they” are to do. The director’s leadership in the management team has an impor-
tant effect on the way team leaders play this role. The director needs to insure that each management team member is responsible for keeping a view of the whole organization, which includes each team.

Working groups on agency issues give team members the opportunity to develop a perspective on the whole organization while they influence its direction and practice.

Team members help maintain the balance by proudly showing the organization signs of what makes them distinctive as a group. Inevitable feelings of competition between teams can be ritualized in agency customs, jokes, and folklore. Social occasions and agency ceremonies strengthen both people’s sense of distinctiveness and their unity when these events include people with disabilities, support workers, and others involved with the whole agency.

Setting and maintaining direction

People involved in supported living need to be proud of what they do. And people involved in supported living need to recognize how easy it is to lose track of direction and compromise values in order to deal with the stress of daily relationships or to deal with environmental barriers. To develop personal and organizational competencies, the agency needs to schedule a balance of activities to affirm and question its practice. Such activities include:

- Small and large celebrations of disabled people’s struggles and victories
- Regular times for retreat and reflection
- Encouraging people to visit and form relationships with people who do similar work in other agencies
- Supporting participation in training and development activities outside the agency
- Regular agency evaluation, designed in collaboration with agency staff
- Encouraging people to balance their commitments to work with other important personal, family, and civic activities

Each activity offers a scheduled chance to affirm what is working well, check direction, question established practice, deepen understanding of values and the tensions the agency’s commitments create, and define the agenda of issues important to the agency’s next stage of development.
Daily interactions are as important as scheduled activities to maintain direction. Effective teams encourage routine discussion to question how well people are listening in assistive relationships and to test the fit between staff activity and what people with disabilities say is most important. In times of crisis and confusion, agency leaders insure that someone actively advocates for the agency's values as people search for solutions.

Maintaining integrity

Many people develop new skills and deepen their maturity through their struggles to provide people with disabilities with good support. No one does the job without confusion, problems, and errors, but people who are capable of doing the job learn from their experiences. When times are difficult for them, they may put other things before their responsibility to the people they support. It's important for colleagues, team leaders, and the agency director to be aware of these times in one another's lives so that they can confront the person involved, offer extra support, or make arrangements for the person to take a break.

Sometimes support work or team leadership simply doesn't suit a person's abilities and gifts. A person who recognizes the mismatch and moves on to other work does relatively little harm. People who keep working despite this mismatch threaten the supported living agency's integrity by putting their own needs and convenience before the needs and preferences of the people they support. The staff person in this predicament will find it as difficult to listen to the people they support and act on their behalf as to honestly share in identifying difficulties and problem solving with team members.

Sometimes a person who offers good support to a particular person lacks the personal integrity to be a constructive part of an agency. Such a person exploits team colleagues and undermines the trust necessary to effective working relationships.

The person whose own needs and interests don't match the demands of supported living work should find other work. Usually such a person will accept counsel, but occasionally it may be necessary for the supported living agency to act formally to terminate someone's employment. Because the agency needs to function on trust, it often take additional time to satisfy an employee's right to written evaluations which document performance problems, formal warnings, hear-
ings, and so forth. Sometimes these more formal procedures do allow a person to accept responsibility for their work, but often they do not.

Sometimes teams develop an agenda at cross-purposes with agency values. Usually this is less a conscious plan than a kind of an unconscious conspiracy. Instead of openly advocating for agency change, a team in this situation hoards its concerns and conflicts as a source of its own cohesion and sense of superiority. Effectively confronting the negative energy of such a group will call on all of the power-within the other people in the agency, especially the director.

The director's responsibility

The director has a particular responsibility to insure that the agency, through its assistive relationships, teams, and working groups, focuses enough power on these five recurring issues to insure that the organization keeps developing its capacity to realize its values. In a sense, the director acts as a trustee of the agency's direction and struggle for the ability to carry out its work without resorting to coercion and fear.

This seems odd from the point of view of a hierarchical organization. Theoretically, in such organizations the board acts as trustee and the director implements the board's policies. The director delegates responsibility and takes care not to scramble proper reporting relationships by becoming involved in matters that belong to subordinate supervisors. In fact, successful supportive living agencies look less neat and clear. Board members have vital roles to play, but they do not simply dictate policy because that would mean imposing unilaterally on assistive relationships and organizing the agency around power-over relationships. Team leaders have crucial roles to play, but the director will from time to time be an active participant in team work and in assistive relationships. In these instances, the director participates as a collaborator even though this may cause some confusion among workers who instinctively identify the boss only in terms of power-over. As much as any other member of the agency, the director who resorts to power-over signals a personal and organizational problem. This apparent messiness may not seem like the way it ought to be in a successful supported living agency, but it is the way it is in at least a few of them.
III. Realizing the promise of supported living calls for new ideas about organization and management

Supported living arises from a reversal of socially devaluing assumptions. Increasing numbers of people believe that congregating and segregating people for care and treatment is unjust and unnecessary. They are convinced that it is desirable and possible for people with developmental disabilities to face the challenges and enjoy the benefits of living in a home of their own. From this point of view, the mission of publicly supported human services turns upside down from a primary concern for treatment, protection and control to a focus on assisting people to establish and live successfully in homes of their choice.

Realizing the mission of supported living calls for new ways to organize and manage work. The images of organization that emerge from innovators’ experiences call for big changes in common assumptions about how to design and manage agencies. Supported living challenges both common ideas about people with disabilities and common ideas about organizations.

Viewing organizations as machines leads to poor understanding of necessary changes

Some of the problems in doing supported living are easy to see. Much of the discussion among people considering the idea concerns important, obvious questions. Can we keep people safe? Can we pay for it? Can we find real estate? Can staff adjust to new job roles and more complicated schedules? What do we do with the money that we've sunk into our buildings? A growing number of agencies have successfully tackled these and other difficult problems and demonstrated that supported living can be done successfully and over time periods as long as 10 years.

As they have solved the apparent problems, supported living innovators have run into additional problems, which lie submerged within a common sense mental picture of how organizations function. Many people take for granted that organizations are like machines, and this limits understanding of what it takes to make and sustain important changes. Managers, workers, and outside advocates frequently picture their organization as a thing outside themselves. In this view, an organization is staff and buildings configured to produce a valuable product. Necessary work is specified, delegated, and coordinated by strategic plans, organization charts, procedure manuals, and schedules. In this apparently rational picture, change means reconfiguring
the machinery by changing schedules, job descriptions, and procedure manuals, often with the help of technical assistants. Staff training adjusts workers to new arrangements. Resistance to change results from poor communication or under-use of authority and is met by sending the message again, clearer and louder.*

Applied to the transition from residential services to supported living, the mental picture of agencies as machines oversimplifies the change process. It suggests that if system managers want a new form of service, like supported living, they should simply change what they buy through contracts or direct expenditure. If system managers want more of some valuable quality, like choice or personal relationships, they change product specifications by changing laws and regulations. The machine picture says that advocates may prevail simply by persuading a court or in a legislative body to tell system managers to tell providers to do something different. When managers who see their agencies as machines get the signal that group homes are no longer a valued product, they try to redirect the organization to produce supported living by changing plans, job descriptions, and procedures. They look to technical assistants to provide models that answer their new questions about how to find real estate, how to design jobs, how to keep people safe, how to give people more choices and a better chance at forming relationships, etc. They rely on staff trainers to “give staff the values, motivate them, and tell them how to make it work.” They speak of “marketing the concept” of supported living to funding agencies and family members.

This oversimplification accumulates negative effects because it leaves out much of what has to change if people with developmental disabilities are to get good support. Organizations aren’t just things out there to rearrange; people belong to organizations and feel the effects of organizational life and change emotionally. Supported living challenges more than schedules, procedures, and job descriptions. It challenges people’s basic understanding of their work and themselves.

Supported living advocates testify to the depth of necessary change when they describe the change from residential service to supported living as a “paradigm shift.” This means, a fundamental discontinuity in the way people understand and respond to situations. This could be a helpful image to guide complex change, but the machine picture of organization abets a misconception that paradigms can be shifted as easily as one changes hairstyle. Everything from the intro-

*For helpful contrasts between the machine image and a number of other possible images of organization, see G. Morgan (1986). Images of organization. Beverly Hills: Sage. Morgan summarizes the machine image in chapter 2 and then explores 7 other, contrasting images of organization. For a useful discussion of the negative consequences of having only a machine image of organization to manage corporate life, see L. Mitroff and R. Kilmann (1984). Corporate tragedies. New York: Praeger.
duction of New Coke and the buttons on the fly of 501 Jeans to the General Theory of Relativity has been enthusiastically publicized as a paradigm shift. This overworks the term well beyond the point where its meaning is exhausted. Overuse misdirects people to underestimate the difficulty of such basic change. Dana Meadows* reminds us,

A paradigm is not only an assumption about how things are; it is also a commitment to their being that way. There is an emotional investment in a paradigm because it defines one’s world and oneself. A paradigm shapes language, thought, and perceptions—and systems. In social interactions, sayings, common sayings, the reigning paradigm ... is repeated and reinforced over and over, many times a day....(p. 3)

This suggests that changing a paradigm involves more than an individual conceptual makeover. It means social activity: building a community of meaning around different emotional commitments, different ways of seeing, and different ways of acting. When the machine image of organization dominates thinking, people simply try to reprogram the old organization with a new concept. The result: more of the same, but with new labels.

New images of organization fit with the reality of doing supported living better than machine images do

The machine picture of organization is popular because it has worked as a way to efficiently program many human tasks. When tasks can be analyzed and sequenced in a routine that permits easy external measurement, an organization can be set up as a simple machine. When the repertoire of standard solutions is extensive and when deciding which solution matches what problem requires expert judgement, an organization has to set up as a professional machine.

Most existing residential services operate with a mix of simple machine and professional machine structures. Direct service work is organized as simple machine work: jobs are specified by procedures and individual program plans. Individualization supposedly results from the activities of professionally organized teams, established by policy to decide which procedures staff should carry out to yield progress toward objectives that the team selects as meaningful. Team judgments and management’s effectiveness in insuring compliance with planned schedules are regularly monitored by outside inspectors who decide whether or not agency performance equals appropriate care and treatment.
Workers who carry out small steps at another's direction experience different status, pay, and working conditions than do professionals who exercise the discretion in the solutions they choose to apply. But both the counterperson at the fast food restaurant and the physician member of an interdisciplinary team who work in organizations structured to develop and consistently deliver standardized solutions to a pre-defined set of problems. Whether the product is tacos or modern health care, the machine organization invests in and rewards convergent thinking toward routine solutions. Proper diagnosis and prescription means correctly identifying a defect and matching it with an approved remedy.*

The machine picture of organization fits poorly when an agency has to solve diverse and novel problems in a rapidly changing environment. One big, non-obvious challenge facing managers who implement supported living is creating and sustaining a problem seeking organization in a system that expects and monitors and values standard performance. This challenge does not arise from reading management books; it arises from the nature of the work that must be done to support people with severe disabilities.

If supported living is going to work for people with developmental disabilities, workers in supported living agencies have to create good and lasting relationships with a variety of different individuals. Through their relationships, staff collaborate with the people they support to identify new problems and opportunities as they come up and to create new solutions as people need them. The fact that the person with a developmental disability usually depends on the supported living worker for essential assistance complicates the relationship. So does the fact that important people outside the relationship legitimately hold the supported living worker accountable for what happens to the person with a developmental disability.

The stakes in discovering new images of organization are high. When a person meets a professional worker or a direct service worker who represents an agency organized around matching people to existing solutions, only the part of that person that fits the menu of available solutions will make sense to the worker. The parts that don't fit within the agency's repertoire will be ignored. A person whose desires can't be made to fit will be sent elsewhere. But most services for people with developmental disabilities are already the elsewhere to which other systems send those whose needs and desires don't fit their preferred set of solutions. So a growing number of people end up
with no alternative. Those who cannot leave and persist in resisting
the organization's preferred solutions risk being rejected by those they
must continue to rely on for the most basic daily assistance. The mu-
tual frustration produced by this interpersonal bind pushes people to
withdrawal, burnout, and violence.

Working in a residential facility, even a very small one, can be like
working on an assembly line. Working effectively in supported living
has to be more like inventing and negotiating solutions to political
problems. When an ongoing fight between a person and her roommate
leads neighbors to complain to the landlord or when a person decides to
stop taking his medication, procedures and past experience may pro-
vide a guide for negotiating a balance among competing interests in a
way that preserves important values, but there are no self-administer-
ing prescriptions.

E.F. Schumacher contrasts convergent problems, which have one best
answer with divergent problems which call for a widening variety of
responses and usually involve dealing creatively with conflicts of value.
Doing supported living means organizing to support people in dealing
with divergent problems. Schumacher* describes the everyday art of
dealing with divergent problems:

...through all our lives we are faced with the task of reconciling
opposites which, in logical thought cannot be reconciled.... How
can one reconcile the demand for freedom and discipline in
education? Countless mothers and teachers, in fact do it every-
day, but no one can write down a solution. They do it by bring-
ing into the situation a force that belongs to a higher level
where opposites are transcended—the power of love.

Divergent problems force people to strain themselves to a level
above themselves; divergent problems demand, and thus pro-
vide the supply of, forces from a higher level, thus bringing
love, beauty, goodness, and truth into our lives. It is only with
the help of these higher forces that opposites can be reconciled
in the living situation. (p. 78)*

The work of supporting people with developmental disabilities
doesn't demand extraordinary creativity; it calls for the sort of ordi-
nary creativity that machine imaged organizations program out. The
important abilities have to do with forming and sustaining relation-
ships, listening and looking and thinking carefully, and inventing
solutions to everyday problems.

* E. Schumacher.
(1973) Small is beauti-
ful: Economics as if
people mattered.
London: Blond &
Briggs.
Experience shows that many ordinary people have the skills and talent to master the art of assisting disabled people to make and keep their place in community. All that is necessary for ordinary creativity to flower is that organizations develop ways to enlist and expand their worker’s commitment to better lives for the people they serve and their discipline in learning to become better collaborators with the people they assist.