

Community Opportunities
Improving Community Living
Options

Final Project Report
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Community Opportunities
PO Box 11204
Blacksburg, VA 24062
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Purpose of the Grant

As stated in the original grant proposal, targeted outcomes of this project were **“to increase consumer direction of services in the community through use of traditional and nontraditional partnerships and resources and address issues of guardianship / authorized representation preventing people from moving into the community or for people without strong family advocacy.”** “Consumer direction” was to occur for people with developmental disabilities living either in the community and determined to be “at-risk of institutionalization” or in a state training center. Partnerships to support the work of the project were formed with Central Virginia Training Center and New River Valley Community Services (“traditional” partnerships) and Wall Residences LLC (a “non-traditional partnership” formed between two community provider organizations). Alternative guardianship and authorized representation arrangements were to be explored within the microboard support structure.

Project goals fell in two categories – establishing microboards for people living in three distinctly different settings/support structures (the training center, Medicaid waiver funded sponsored residential services, or in the community with only case management as a formal support) and testing guardianship / authorized representation within the microboard structure. Both broad goals were intended to substantially increase the person-centered support options available to people with developmental disabilities by expanding use of the microboard model, testing its applicability to distinctive support needs.

The microboard model is unique because it builds structure into the amorphous concept of a “circle of support” (or “circle of friends”). While circles can function as extremely creative support networks, they often form during a time of transition or crisis in a person’s life and, despite their inherent flexibility and individualization, frequently don’t maintain over time. The incorporated microboard, whose mission is to provide support and empowerment to one individual with a disability, exists as a legal structure and therefore can serve multiple roles including, in other states and countries, acting as a licensed provider of residential support for one person or, within a system of individualized budgets and budget authority, utilizing a fiscal intermediary to manage and direct all support with and for a person receiving publicly funded services. In Virginia, the model has given structure to the “circle” concept, creating a support network which will exist throughout the life of the person with a disability (with most historically having been created for people who have a limited number of intact, though disconnected, relationships with family and/or friends); however, other means of utilizing the incorporated status of the microboard had not been explored, nor had microboards been developed around the most marginalized and at-risk individuals.

This project sought to create new options in both arenas by exploring ways to utilize the microboard in assisted decision-making and with people who are

extremely isolated. The project met with very mixed success in both areas, encountering numbers of unanticipated barriers to providing person-centered and consumer-driven support to people with developmental disabilities. A primary impact of the project was to create a new dialogue at many levels across the Commonwealth about systemic barriers to person-centered and consumer-driven support, with greater interest in how microboards, as one among a “menu” of support models, might play a role as Virginia begins to experience a shift toward a real commitment to both a philosophy and practice of helping people with developmental disabilities have lives of their choosing in local communities.

Outcome Performance

Accomplishments:

The first broad goal was to establish microboards for training center residents (three to four microboards), people receiving sponsored residential services through Wall Residences (four microboards), and people receiving case management through New River Valley Community Services (NRVCS) (three to four microboards), with all participants either institutionalized or at-risk of institutionalization.

A total of 12 people with developmental disabilities and meeting the “at-risk” criteria participated in the project, four through each of the partner agencies, with six involved during the first year of project activity and six additional people included in Year 2. Through the project, two incorporated microboards were created, and an additional three circles of support (formed as the foundation for microboards) planned to incorporate within several months following project end.

CVTC participants

Substantial project outcomes were obtained for just one of the three training center participants, and microboard incorporation could not reasonably be anticipated in the near future, even for that one participant. All preliminary activities to direct person-centered discharge processes were conducted for all four participants.

Year 1 participants -

- For one of the Year 1 participants, recruitment and development activities occurred across the first year, alongside the discharge planning process, to identify potential microboard members and gain the support and involvement of the community provider. However, the participant was returned to the training center after a brief community placement mid-way through Year 2, and microboard development was ceased in accordance with an appointed public guardian’s decision.
- For the other Year 1 resident, the decision was made by an appointed public guardian and CVTC staff, in the summer of 2007, to pursue discharge to Southwest Virginia Training Center, rather than a community placement. Involvement with the project was, at that point, ended.

Year 2 participants -

- Both Year 2 participants were successfully transitioned to community placements.
- For one participant, dramatic improvements in life quality were measured and an Essential Lifestyle Plan fully developed. Circle of support membership included CVTC staff and former staff and newly developed community relationships. While microboard development moved much more slowly than anticipated in proposed timelines, the circle foundation was built and project staff planned continued microboard development activities following completion of the grant funding period.
- Little progress was achieved with the second Year 2 participant (identified by CVTC staff in the last half of Year 2). The participant's few ties to the community were identified, and a family member and the community provider agency (not a project partner agency) were given information about circles and microboards as person-centered support mechanisms, but with no agency or personal champion in place, no additional circle development was achieved.

Wall Residence participants

Strong circles of support were developed for three project participants. Two moved ahead with microboard incorporation, and the third circle planned to incorporate within three months following project completion. Preliminary activities to direct and advise person-centered circle and microboard support were conducted for all four participants.

Year 1 participants -

- Circles of support were recruited for both Year 1 participants. One circle, in which membership solidified after the first year, moved ahead with incorporation in the second year. Circle members were recruited from within the residential provider staff networks, some of whom were already acquaintances, though not friends, of the project participant. The relationships within the microboard were extremely significant in the life of the participant, replacing ties with family members lost over recent years.
- The second Year 1 circle membership was, by project end, at the point of stability which would support incorporation within several months. This participant had no connections outside paid staff prior to the project, and circle membership was developed through a staff member's community connections. Facilitation of a strong circle moved much more slowly than originally anticipated, due to provider reticence about the project, but new relationships coalesced in Year 2 and project staff planned to continue microboard development following project completion.

Year 2 participants -

- In Year 2, one of the circles formed quickly and moved ahead to incorporation. The participant had formed many meaningful relationships in the past but connections had been lost over the course of numerous moves, especially as the result of the most recent move to a provider in a

new community. Circle facilitation brought members back in connection with the participant and each other.

- Circle members were recruited and initial meetings conducted for the second Year 2 participant. However, microboard development activities ceased based on the residential provider's decision that a microboard would not be appropriate for the participant.

NRVCS participants

Circles of support were developed for two of the four project participants residing in the community and receiving case management support. Of those, one planned to move toward incorporation within a couple of months and the second within several months of the funded project period. Preliminary activities to direct and advise person-centered circle and microboard support were conducted for all four participants.

Year 1 participants -

- One participant during the first project year removed herself from the project after getting married and deciding she was no longer in need of a larger support network.
- Ongoing, diverse attempts to help the second Year 1 participant build connections with community members and develop a circle of support were unsuccessful. Numbers of relationships were initiated but discontinued.

Year 2 participants -

- Circles of support were developed around both Year 2 participants, helping both to reconnect with family members. While project involvement assisted one circle composed primarily of extended family members to practice new effective communication patterns, circle development for the participant slowed as circle members coped with the ongoing difficulties inherent to supporting a family member with significant mental health support needs. The circle planned to expand to include at least one additional non-family member prior to incorporating within several months of project completion.
- Prior to this project, the second Year 2 participant had numerous connections in the community (through involvement in two separate churches) and an extended family with which limited, infrequent contact occurred. None of these three groups knew or had any contact with the others. When the participant began experiencing progressively significant health issues throughout the fall of 2006, no one knew to whom to turn. By project end the participant had an extremely involved, active circle, with a microboard ready to apply for incorporation within a couple months.

The second goal area focused on testing guardianship and authorized representation within the microboard structure. In developing the project proposal, agency partners agreed to identify project participants in need of decision-making support. Prior to the project, no participant receiving support through Wall Residences or NRVCS had yet been evaluated and determined to

lack the capacity to make informed decisions. However, staff of these agency partners recommended some participants for the project because they were concerned about the participants' needs for substitute decision-making. Within the pool of four CVTC participants, training center staff had evaluated two of the participants and determined they lacked the capacity to consent or authorize disclosure of information and were, therefore, in need of substitute decision-making. The other two participants already had appointed guardians.

An anticipated outcome of the project was a test court case, seeking the appointment of a microboard as guardian for a project participant in need of a substitute decision maker. This did not occur with either of the two CVTC participants in need of a guardian; the training center instead petitioned for guardians through the Commonwealth's Public Guardianship Program and public guardians were appointed in both cases.

However, a positive accomplishment with many other project participants came about through education to project staff, partner agencies, circle/microboard members and participants about guardianship alternatives and the roles microboards can play in providing support in decision-making. By fully utilizing other substitute decision-making supports, including powers of attorney and authorized representatives, microboards can promote a high level of consumer direction while, at the same time, offering any targeted, specific decision-making assistance needed. A projected project product, initially envisioned to be a "how-to" manual to assist microboards in pursuing guardianship, instead developed as a guidance document explaining guardianship and its alternatives and the role of microboards in promoting and supporting the highest possible level of consumer direction by using the least intrusive form of decision-making assistance appropriate for an individual.

Demographics:

Disability Descriptors

All 12 project participants had labels of developmental disability and all were institutionalized or at-risk of institutionalization.

- Eleven participants had labels of intellectual disability, eight with a mild to moderate level of disability and three with a significant level of disability.
- Ten participants had concurrent mental health diagnoses, two having been hospitalized one or more times for inpatient psychiatric care.
- Two had extensive support needs based on physical disabilities and one due to sensory impairment.
- In addition to the four participants who were CVTC residents at the outset of their involvement with this project, two other participants had been institutionalized in a state training center in the past.

Gender/Age Descriptors

- Six project participants were female and the other half male.

- Ages of participants ranged across more than a 40-year spread, with three participants in their 60's, four in their 40's, four in their 30's, and one in his mid twenties.

Geographic Descriptors

Project participants were from central, Southside, and southwestern Virginia. The four CVTC residents were primarily from central Virginia, with one originally from the far southwestern part of the state. The four participants receiving support through Wall Residences lived in Southside (Danville and Chatham), central Virginia (Lynchburg area) or Southwest (New River Valley). The remaining four received support from NRVCS and lived in the New River Valley.

Consumer Participation:

People with disabilities were involved in the project on two levels – as project participants and as members of the Advisory Group.

Of the six participants most actively engaged in the project at project end, five were able to voice their satisfaction with their own circles/microboards. One participant used primarily gestures, head nods and eye contact to express likes/dislikes. His general ease with circle members was interpreted as an indication of his positive regard for their involvement in his life. The other participants stated either positive or very positive feelings about having friends and/or family members more involved as a result of the project.

Participant Example

One participant, who lived in an assisted living facility in the community, was institutionalized and separated from siblings during late teen years following the death of both parents. While one brother served as payee and had brief, regular interactions, contact with other family members was extremely infrequent. At a birthday party held by circle members near the end of the project for the project participant, the participant was asked about a gift and replied, loudly and definitively, "It's my family!", having received a photo album with family photos from a sister-in-law. The brother, sister-in-law, their son, daughter-in-law and two grandchildren had seen the participant only at brief Christmas gatherings in prior years. Through the project, they became active members of the circle, including attending the birthday party. Their reconnection mattered deeply to the participant. The party was made all the more special by the presence of a room full of other friends from the two churches attended by the participant. On the way home after the party the participant repeated, "They're my friends. All my friends came to my party."

Two members of the project Advisory Group had disabilities and were also members of the Community Opportunities Board of Directors. They participated in Advisory Group meetings, receiving updates on grant progress and barriers encountered. One Advisory member, who was institutionalized for decades, was

especially interested in supporting the work of the project, having a real commitment to seeing all institutionalized people with disabilities “freed” and given the opportunity to live in the community.

Barriers:

Numerous unanticipated barriers to projected activities and outcomes were encountered. Some barriers were specific to the project while others were systemic in nature.

Agency and Project Specific Barriers

1. Lack of personal champions. Microboards are incorporated from strong circles of support, and the building of circles is a time intensive process. Only through the commitment of time can all members of a circle develop trusting relationships with each other and with the focus person, driven by a vision of a positive future and the path to be traveled to build that enviable life, and grounded in opportunities for mutual support, a shared affirmation of lessons learned as differences of opinion are processed and barriers or struggles are encountered and resolved, and regular celebration. Because the project was time-limited, it was anticipated that circle building for such isolated people would require a personal “champion” to help identify any current or past relationships and aid in recruiting new contacts. This was especially critical for participants outside the New River Valley, in areas project staff had no community contacts. Though delineated in the original proposal and clarified with all agency partners in both years of the project, agency partners did not choose participants with champions nor did they, in most cases, require or encourage a staff member to act as that champion. In cases where no friend, family or staff member was personally invested in the development of a circle and microboard, recruiting circle members was an extremely slow, difficult process. Exceptions occurred with two of the Wall Residences providers. Once these providers were committed to circle development, both were instrumental in identifying and recruiting potential circle members, with one microboard resulting and the other circle close to incorporation. Another Wall participant had two friends who had lost contact with the participant over the years. Once reconnected, they served as champions, and the rest of the circle quickly formed. In the fourth case involving a strong champion and successful circle/microboard development, a woman recruited by project staff agreed to serve in that role for one of the NRVCS participants; again, the circle came together rather quickly once someone in the community was actively engaged and committed to circle development.
2. Individual provider autonomy and resistance. While the Wall Residences directors were extremely invested in the project goals and potential changes within their agency’s practices, the individual sponsored residential services providers within the agency were, in all cases, resistant to the development of

a circle and microboard. They voiced their mistrust of this group of people having input into decisions made about the services provided to the focus person. With project staff, the agency directors were involved in helping these providers become more comfortable with seeing the circle/microboard as an important tool to support person-centered and consumer-directed services. However, within agency and licensure policies and regulations, individual providers operate with a high level of autonomy, and the required paradigm shift at best took considerable time to make; at worst, was never made and resulted in a provider's decision to end the participant's involvement with the project.

3. Institutional inflexibility. While CVTC administrative staff supported the project concept, some training center internal policies and practices limited project effectiveness.

Identification of project participants was an extremely slow process, falling far outside projected timelines. To be involved, the facility's discharge coordinator sought consent from a resident's Authorized Representative, if one had been named. At the start of the project, the great majority of CVTC residents had Authorized Representatives, and, with the expansion of the Public Guardianship Program, public guardians were then sought for all but one resident without an Authorized Representative. "Advertising" the microboard model and project to Authorized Representatives was done by the discharge coordinator; project staff had no access to those family members. No other process for helping family members begin to appreciate the positive possibilities related to the development of a circle/microboard could be developed. A significant "learning" for project staff was a fuller understanding of the very powerful role played by Authorized Representatives in the lives of facility residents. If an Authorized Representative blocks discharge planning, the resident loses every right to explore and learn about options or make any choices about having a life outside the training center unless the resident has strong formal communication skills and can advocate effectively for his/her own desires. This formidable barrier to community placement for training center residents cannot be overemphasized.

Once discharge planning was initiated for a project participant, typical facility practices were followed. Project staff was given little opportunity for involvement in discharge planning. For example, staff typically received late (if any) notice about the discharge planning meetings. In one case, discharge occurred with little real understanding of the project or buy-in on the part of either the community provider or the participant's guardian. Because the participant in this situation was not identified for project involvement until the final quarter, the project ended before the guardian, who was involved in the participant's life on an extremely limited basis, could be contacted by project staff or would agree to any involvement in circle development.

A primary impediment to the work of the project involved the never-ending “loop” experienced in attempting to plan creatively for the two Year 1 training center participants who did not, in Year 1, have Authorized Representatives. The two were identified for the project because no Authorized Representative was in place and with the intention of exploring ways the circle and eventual microboard could serve in that role. However, circle members could only be recruited in the community to which the participant would move following discharge (to have an ongoing relationship with a person circle members must, logically, live geographically close to the person). No decision could be made about the community to which the resident would be discharged, because the training center staff would not hold conversations with prospective providers to make even preliminary decisions about placement options without consent for a release of information. Informed consent could not be given because no Authorized Representative had been named. The stalemate around this issue blocked project activities for the two participants.

A final issue related to training center practices involved staff time committed to the project. In the project proposal, the training center committed to a .375 FTE in-kind contribution of staff time. However, the role played by staff seldom stepped outside the typical discharge planning process for an individual and ended within the typical discharge/follow-up time frame. Limited staff time and involvement significantly impacted project activity.

Systemic Barriers

1. Lack of commitment to person-centered philosophy and practice. A significant barrier encountered repeatedly across the course of the project was the absence of person-centeredness in agency partner philosophy and practices. This fundamental reality played out across community providers and the training center. While project staff had extensive experience in multiple roles in Virginia’s disability services systems prior to this project, a major downfall of the project was the considerable underestimation of the extent to which the absence of this basic construct as a foundation to “how we do things here” could negate support for the microboard model as a tool in facilitating consumer-driven services. In retrospect, it was clear to project staff this foundational work in person-centered philosophy and practices should have been laid prior to the work of this project.
2. Public guardianship. Virginia’s Public Guardianship Program was developed to meet very real needs among some of the Commonwealth’s most vulnerable citizens. Having a “guardian of last resort” alternative available may be a necessary option in a limited number of critical situations. However, expansion of the Public Guardianship Program occurred concurrently with this project and allowed CVTC staff to utilize that program instead of the volunteer guardian program already in place at the training center. When the project encountered the Authorized Representative stalemate (described above),

CVTC staff agreed to recruit volunteer guardians, with the goal of then moving ahead with discharge planning, recruiting a circle/microboard, and, as a test case, petitioning for a change in guardianship to replace the volunteer guardian with the microboard. Once, however, a decision was made by the facility staff to pursue public guardians and the programs were appointed, microboard development was blocked for both CVTC participants in question. In one case, the public guardian was unwilling to consider a change in guardianship (to a microboard, once established) and refused to consent even to any microboard development for the ward. In the second case, CVTC staff and the newly appointed public guardian made the decision to pursue discharge to Southwest Virginia Training Center rather than a community placement, thereby negating the purpose of the participant's involvement in the project.

Plan for Continuation:

The two broad categories of project activity – microboard development/incorporation and expansion of the use of microboards with substitute decision-making – both had components which were not accomplished by project end. Of the original 12 project participants, two had incorporated microboards and four more had circles in development. At least three of those will be ready to incorporate within several months of project end, with the fourth possibly requiring a greater investment of time. Project staff will continue to provide facilitation to these four circles, as they continue to strengthen as cohesive support systems, and then initiate the incorporation process. Additionally, the two incorporated microboards will continue to receive intermittent training and/or facilitation as needed and requested as they encounter new situations or support issues.

As the project developed, the goal to meld microboards with substitute decision-making broadened to focus on promoting, within circles and microboards, the consideration of the broad array of decision-making supports available. The guidance document developed through the project, “Substitute Decision-Making and Microboards: Guidance on Promoting and Supporting Self-Determination,” was incomplete at project end because a court case testing the appointment of a microboard as guardian had not yet occurred. Once tested in Virginia's courts, additional information will be added to the guidance document regarding the process involved for microboards to petition for guardianship as one among the array of decision-making support options.

Staff time required for activities to further the work of both project goal areas will be funded through Community Opportunities' ongoing development and fundraising work in southwest Virginia. Because no public (Medicaid waiver) funding stream exists to finance the work of microboard development and facilitation, the organization exists through ongoing fundraising work. The organization's Board of Directors, through its involvement with the project's Grant

Advisory Group, is committed to the long-term support of project participants and project work in the area of assisted decision-making.

Effective Strategies:

1. Involvement of community champions. Individual champions and circle members who became invested in the life of a person with a disability and then to others in a circle, sharing a commitment to work together, overcame the barriers of social isolation experienced by the project participants and, in some cases, the resistance of the providers involved. A woman recruited by project staff developed a friendship with a NRVCS participant and became the champion who helped draw other circle members together. At the participant's birthday party, this community member remarked on how meaningful it was to the participant to have such a turn-out of family and church members, people who had become truly invested in the work of the circle in honoring and supporting the participant's dreams and preferences. The woman expressed her surprise at the very positive outcomes for the participant, stating "I'm the biggest cynic in the world about this stuff..." and had not anticipated the number and strength of relationships developed. When offered the opportunity to connect with people with disabilities in meaningful ways, community members can truly rise to fill some of the voids in Virginia's overtaxed services system.
2. Attorneys as project advisors. The two attorneys who provided consultative support to the project and who'd had no previous experience with the microboard support model became highly invested in the project outcomes. One of the two attorneys had served as guardian for a woman in the community with whom she became involved while acting as Guardian ad Litem for the woman for whom no "guardian of last resort" could be identified. Because the attorney had personal experience with the loneliness and isolation experienced by adults with intellectual disabilities struggling to live independently in the community – and knew firsthand the difficulty of being the sole supporter when not involved in some larger support circle or microboard – the concept of microboards assisting with decision-making made intrinsic good sense to her. Over the course of the project, the two attorneys became ambassadors for the project, resulting in one attorney volunteering her time to present on the project's goals and outcomes at the 2007 Joint Conference on Guardianship, Elder Rights and Disability Services. Both attorneys also facilitated a meeting between project staff and the director of one of the Public Guardian Programs, attempting to establish a dialogue and openness to developing a means for the microboard model and public guardian programs to work together. If alternatives to guardianship are to be fully promoted in the future, attorneys open to understanding and supporting use of the broad array of options could serve as real catalysts for change.

3. Small provider flexibility. As stated earlier, the Wall Residences directors were extremely committed to the project outcomes and exhibited significant flexibility in revising their agency's internal policies and practices to incorporate more person-centered and consumer-driven supports. For example, a barrier to relationship development was encountered for one of the participants because policies prohibited the participant from being transported by friends or staying overnight with friends if medication needed to be taken while with them. One of the Wall directors worked with their local licensure office and revised their policies/practices to remove these barriers. Creating more person-centered and consumer-driven supports within existing community providers may, in some cases, be much more effective than working toward that change in the institutionalized practices of the state training centers.
4. Key change agent involvement. The involvement and support of staff of the VBPD and both the Office of Mental Retardation and the Office of Human Rights (within DMHMRSAS) was instrumental in reaching the project outcomes achieved. This interest created opportunities to examine the Department's Human Rights Regulations to determine systemic barriers to the use of circles and microboards in substitute decision-making. The interest and involvement of the Office of Human Rights was an especially unexpected and noteworthy outcome of the project and one which can be hoped to bear fruit in future efforts to expand and create regulation and policy which do not prevent people with disabilities from having a high level of choice and control in their own lives and instead promote a person-centered philosophy as the basis for all services and supports.
5. Relationship building. A final effective practice centered on the time invested by project staff in building collaborative relationships with a variety of key stakeholders, including private providers (project partners and others), attorneys, and DMHMRSAS staff members. Even as relationships are central to the concepts of support circles and microboards, so these relationships were foundational to the work of the project.

Recommendations for Future Activities

1. Commitment to person-centered philosophy and practice. As mentioned previously, a central project failing was to significantly underestimate a widespread commitment to person-centered philosophy and practice across Virginia. The project attempted to expand use of one tool for person-centered support when across communities and providers – public and private – there exists little or no commitment to the use of a framework of person-centered planning and self-determination to protect and promote the rights of each individual. To expand the use of any person-centered tools such as circles and microboards, this systems change effort must first occur. DMHMRSAS, DMAS and other stakeholders are currently involved in activities as follow-up

to an initial report documenting a joint review of the MR Waiver, directed by the 2006 Appropriation Act, to determine how it can be improved to provide a person-centered, individualized support focus. Advocacy by the VBPD and other stakeholders may help to ensure implementation of key recommendations of the Person-Centered Leadership Team. The work of this group has included examination of diverse policies, regulations, funding streams and practices which currently inhibit person-centeredness in services; change across the gamut will be necessary to effect real systems change in Virginia. A related recommendation is for systemic training in person-centered thinking, planning and support. This training is critical to begin ensuring true consumer-direction, where each person's voice is heard and people are given the chance to make as many informed decisions as possible. Potential training targets include the Public Guardian Programs; private providers; training center staff and family members / Authorized Representatives; and people with disabilities.

2. Human rights regulation review. A second systems level recommendation is for a continued examination of the Commonwealth's Human Rights Regulations governing the services and supports provided through DMHMRSAS. While the regulations have just recently been reviewed and revised, a conversation begun now by key change agents in Virginia could effect the paradigm shifts required to result in truly substantive change prior to the next required review period. Reliance in Virginia on widespread use of Authorized Representatives and guardianship significantly limits the opportunities of citizens with intellectual and other developmental disabilities to lead self-determined lives. Across the country, states have begun reexamining their overuse of guardianship. In Wisconsin, that study resulted in the following findings:

"More people have guardians than need them. In the vast majority of cases – over 90% in one study – those who have guardians have full guardians, with no legal rights to make decisions left to the person. Even where the person retains some rights, the rights retained tend to be those listed on the court forms: voting, marriage, holding licenses, and making contracts. Basic human rights, like the rights to go where the person wants, to choose his or her own friends, and to be alone in privacy with other people, are not even discussed as part of the process. This pattern has major costs, in terms of our basic concepts of human liberty, in terms of the person's ability to develop to their full potential, and in terms of the extent to which decisions made reflect the preferences, hopes and dreams of the person whose rights the guardianship is supposed to protect."¹

Likewise, the use of Authorized Representatives has resulted in situations, such as the training center discharge process, in which a person with a

¹ Froemming, R. (2002). *Making a difference: Thinking about decision-making support in the transition process* (p. 4). Madison: Wisconsin Council on Developmental Disabilities.

disability can be stripped of all authentic voice if determined to lack the capacity to give informed consent. Much of the practice around substitute decision-making creates all-or-nothing determinations, rather than viewing “assisted competence” as the way most people typically use their own “support circles.” Policy and regulation, to support person-centered and consumer-driven services, must promote an array of decision-making options.

3. Linkages with public guardian programs. While the Public Guardian Programs have recently received additional funding, allowing them to serve many people with intellectual disabilities on their waiting lists, such lists will grow in the future as those currently receiving services stay on the Program “rolls” throughout their lifetimes. Once tested in Virginia, the use of microboards as guardians may serve a useful role by easing the strain on the Public Guardian Programs. Microboards could be developed around people with intellectual disabilities for whom Public Guardians have been appointed, with a change in guardianship sought once the microboard is established. If successful, this practice would create space in the Public Guardian Programs for additional people in urgent need of that “last resort” option, while at the same time creating a network of support around extremely isolated individuals. Project staff will continue working to establish a linkage with one or more Public Guardian Programs.
4. Microboard development with family sponsored residential services. Wall Residences directors and project staff have committed to exploring the development of microboards, targeting the Wall Residences family providers of sponsored residential services. The family providers often have been appointed as guardians of their adult sons/daughters so are not only parents/guardians but also control all the services and supports received. The Wall Directors – and some of the providers – are uncomfortable about the very closed nature of this support system and are open to considering the role of microboards to expand the number of relationships in the life of the person with a disability and honor the person’s dreams and preferences.
5. Bridge building program development. While Community Opportunities historically has been involved primarily with transition age young adults having some level of family involvement, the organization has long held a commitment to the development of circles and microboards for people who are the most marginalized and isolated. This project underscored the difficulty of circle/ microboard development for people who have extremely limited relationships. The organization will explore the development of a separate “bridge building” component, utilizing volunteers to help people become involved in community activities on an ongoing basis as a means of establishing relationships. As the individual becomes a “regular” at a community activity, people newly met can be invited to join a circle of support. As funding is available, this option will expand the opportunity for circle/microboard support to those most in need of a support network.

Assessment of Systemic Impact of Grant

A primary impact of the project was to engage players at many levels across Virginia in a new dialogue about systemic barriers to person-centered and consumer-driven support. Virginia is beginning to experience a shift toward a real commitment to both a philosophy and practice of helping people with developmental disabilities have lives of their choosing in local communities. Via this project, circles of support and microboards are now viewed by many as tools within an array of options for assisted decision-making and self-determination.