

**A Circle of Friends:
Microboards Make Sense in the
Amputee Community**

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Since the 1970s, the trend in the human services profession has been to reduce reliance on institutional settings in favor of smaller, community-based options. Still, for families seeking truly person-centered planning for loved ones with a disability, the care offered by traditional support agencies often falls short. The result is that people feel isolated and depressed, with little hope for meaningful relationships, true vocational rehabilitation, or other resources and connections that could dramatically improve their life.



A New Concept Is Born – and Grows

In the early 1980s, David and Faye Wetherow of Manitoba, Canada, pioneered one of the most progressive and promising new concepts in person-centered planning: microboards. As the popularity of microboards spread into the U.S., the

self-directed support corporation (SDSC) was also developed (same concept, different name). A microboard or SDSC is composed of a small group of committed individuals (family and friends) who form a legal entity, or agency, that cares for an individual with a disability. The legal entity receives the government funding needed to care for this person. This takes the place of state or federal dollars going to an agency caring for many people, where the agency assumes control of resources and care.

The core of this concept is that, regardless of the nature of the disability, the individual will be more in control of the care he or she receives or chooses not to receive, and the loving network of friends and family members will actively plan for that care. But David emphasizes that it goes far beyond simply providing better services for an individual; it's also about creating situations where the person at the center of the microboard can experience life to the fullest by engaging in an ever-widening community of love and support. In that light, people don't just exist – they thrive.

Broader Applications

So, what does this mean for the amputee community?

Even though the microboard concept originated on behalf of people with developmental disabilities, the methods are in place to effectively allow a microboard to form around anyone with a severe or chronic disability.



For example, while the most immediate challenges to a child with severe limb loss may be those of mobility, a microboard can help with a host of other potential issues, such as coping with emotional pain and reaffirming self-image. As the child grows into adolescence and adulthood, the microboard could help with vocational direction or provide support in the event that the child's parents pass away.

In fact, David eagerly supports the creation of a support system like a microboard even if the group doesn't become a legal entity to receive funding. Even if a person

is relatively self-sufficient, the model can still introduce positive people and experiences that have a mutually beneficial effect on the individual and the expanding, surrounding community. “It’s future-building,” he says.

With 70 percent of amputees age 50 or older, microboards can also help seniors. “Elders face difficulties with their capacity to move and, more importantly, with social isolation,” David adds. “Medicaid home-care support can be obtained, but without a microboard or intentional circle of support, the person might be just as isolated. The idea is to take the same traditional support and use it in tandem with a small community.” With this approach, the whole family wins. The family enjoys more connection, and the senior feels less isolated.

David has seen the microboard model used in many fields of human services, which Charlene Whelan, health educator for the Amputee Coalition of America (ACA), has also experienced. In her previous work with the Alzheimer’s Association of East Tennessee, she discovered that a new community of support was needed for someone who was dealing with her husband’s recent diagnosis of dementia. “It continues to be an invaluable community of support, helping

caregivers deal with both the things they're up against now and preparing for adversities they'll have to face in the future," she says.

Since each state maintains its own regulations, some microboards will have to adhere to a minimum number of formal meetings and a minimum number of members. The Vela Microboard Association of British Columbia has become the model microboard association of Canada and has created affiliate programs to help people in other parts of the world learn how they can form microboards and navigate the setup process. Vela's executive director, Linda Perry, emphasizes that microboards are not about creating rules and regulations in people's lives, but rather about creating meaningful relationships to help all involved.

"The relationships of those in a microboard need to develop naturally," Linda says.

"Microboards are free to create as many formal meetings as they want above the minimum number that their state or province requires, but we see that it's more important that they do things to foster friendship, such as invite one another to dinner. That's where relationships develop."

While Vela's recommended number of members is between five and eight, Linda says it also depends on the individual's needs. For example, someone from a culture that values large social gatherings may benefit from having more than eight members. "I know of one person that has 15 people on their board, and that works very well for them," she adds. But microboards aren't necessarily for everyone. "Someone who is very private ... may not feel comfortable with others being involved in his or her care," Linda says. However, she continues, "microboards have worked well for many people who I would not have guessed. It is not useful to anyone to make a guesstimate about whether or not a person will benefit. It is ultimately a personal decision, and each case requires an individual approach."

Microboards in the U.S.

Although the concept is over 20 years old, it only began to catch on around 2000 in the U.S. Several states now have microboard associations ready to help people with the paperwork and resources involved in setup. Since any state that has long-term care agencies can also have microboards, David wants to reassure people who may want to set one up but don't know how. "In every state, there are people who

know how to make this happen, and once the first microboard is created, the rest can be set up very easily,” he says.

One word of advice he offers is for people to establish a nonprofit corporation, not a charitable organization, or 501(c)(3), which is actually much harder to establish anyway. “However,” he adds, “there’s no need for people to feel that they have it all figured out before they begin the process. We’re still learning new things all the time.”

The Tennessee Microboard Association (TMA), which got its start-up grant from the state’s Developmental Disabilities Council, enjoys being in a state that has had huge success with microboards. With 31 microboards statewide, Tennessee is the most active state in the microboard movement.

Lorre Leon Mendelson, statewide field organizer for the TMA, says that the organization “helps people walk through the process step-by-step.” A direct measure of their results is that, so far, every microboard that has applied in Tennessee has been accepted.

“What’s also great about Tennessee,” David notes, “is that they have placed PATH at the center of their development process.”

PATH (Planning Alternative Tomorrows with Hope) is a person-centered planning process that builds community commitment. It focuses on the dreams and goals of the person at the center of the microboard and helps people achieve what they want in life. Lorre, who has led many PATH sessions, explains: “It doesn’t matter whether or not someone else thinks the person’s goals are realistic or not. The board’s function is to create opportunities for those goals to be actualized.”

David says that the PATH process (created by Jack Pearpoint, Marsha Forest and John O'Brien) is an important element to enable microboards to “take the place of a traditional service provider without distorting the concept of an enduring circle of support.”

Never Lose Sight of the Center

While the microboard can function without changing the government's regulations and legislation, distortion can happen if the microboard sees itself as just a small service corporation. The microboard must never lose sight of the reason it formed in the first place or of its most basic principles: Only one person is at its center and the circle stays focused on that person's vision.

David remembers one group that called itself a microboard, but it was actually serving 17 people. He was not surprised to learn that this type of structure had its run of problems.

His description of the concept is simple but powerful: "Microboards move authority, responsibility and accountability from the agency into the hands of the people with disabilities and their allies, and they do so by having a single person at the center."

As microboards have changed many individual lives, the movement is also changing how agencies deliver care as they realize that many people are leaving the traditional service providers. Charlene Whelan believes that microboards can offer amputees a unique form of empowerment.

“It is empowerment within the context of a community, and that ties in beautifully with ACA’s mission,” she says. “We don’t want to simply help people with amputations to ‘cope’; we also want to see them rebuild a life through which they can thrive. Microboards are a great pathway to doing just that.”

Related Resources

Center for Self-Determination
www.self-determination.com

Community Works!
www.communityworks.info

Inclusion Research Institute
www.inclusionresearch.org

Tennessee Microboards Association, Inc.
Dr. Ruthie Marie Beckwith, Executive Director
www.tnmicroboards.org
empfanatic@aol.com

Vela Microboard Association
www.microboard.org

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http://www.amputee-coalition.org/inmotion/jan_feb_07/microboards.html