

Self-directed Support Corporations (SDSC) and Microboards What A Difference a SDSC Can Make: Joshua's House Incorporated! By Jackie Golden

Self-directed Support Corporations (SDSC's) and Microboards share the same philosophy. Simply put they are a small legal provider for one person with a disability, but then again, they

are much more than that. Both the SDSC and the Microboard put control and direction of supports back in the hands of the person with the disability needing the supports. Both the SDSC and the Microboard follow an incorporation process and develop a not for profit agency. A board of directors oversees the SDSC and the Microboard. The board members consist of trusted allies of the person with the disability. A person with the disability then has a support network of people that believe in them. It is SELF-DIRECTED because the "Board", who receives its direction from the person, decides what supports are needed and how supports are used. These supports are custom designed around the person's wants, dreams and needs.

Brief History:

The history of the Microboard started with David and Faye Wetherow in Manitoba, Canada. David and Faye formed the first microboard around a young man leaving an institutional setting (Microboards and Microboard Association Design, Development and Implementation by David and Faye Wetherow : <u>www.communityworks.info</u>) David and Faye were also instrumental in providing the format to maintaining the critical requirements of the Microboard concept. Those critical requirements are:

- 1. An unencumbered focus on the identity, needs and express wishes of the person who is supported;
- 2. Development and maintenance of an active, diverse and fully engaged citizenbased circle of support (Board of Directors);
- 3. Retaining all possible elements of control, especially including the role of employer-of-record.

David and Faye began a change in the way supports were designed, directed and controlled by the individual. It doesn't matter what you call these entities, SDSC's or Microboards, the key is that they be committed to the person that they were designed for and that they serve only one person.

How Does a SDSC work?

Each State in the United States has procedures and regulations in becoming long-term care providers. The SDSC follow those same procedures and regulations. The only difference is that the SDSC only designs supports for one person, rather than hundreds. Like other providers the SDSC has to follow the state guidelines, regulations, inspections

(if required), as well as federal guidelines. This way the SDSC is accountable for public dollars spent and also accountable to the person that is being served with those public dollars.

There have been questions around the SDSC and Microboard concept. One question is "Does the State have to do something different within their regulations or waivers to allow the SDSC or microboard to form?" The answer is simply, no. If your state has long term care providers, then they can also have SDSC's or Microboards. They are the same as any other provider that follow the same set of regulations. Some States have "waived" some requirements for the SDSC and the Microboard, because these requirements didn't make sense for a provider agency of one. The SDSC and the Microboard must provide quality services, maintain a fiscally responsive system and assure accountability at every level to the state and federal governments.

The SDSC and Microboard approach is quickly gaining popularity across the United States as this approach offers many things to a person needing supports. The best thing is more control and freedom over their own life. People that care about them, not people that don't even know them, assist them in the arrangement of personal supports. We all know that we are better off when you have people that care about you in your life. In addition this approach provides accountability to the state and federal governments. Creating a win-win situation for a person with a disability, their trusted allies (friends and family) and the government.

So you may ask "Is the SDSC or Microboard model for everyone?" The answer to this question is also, No. This concept should be viewed as another option. The problem with our systems has always been that we approach supports as a "one size fits all" model. Over the years we have discovered that this approach doesn't match the person, but also it is a costly mistake. So the SDSC or Microboard may not be for everyone, but for those that have ventured down this path, the changes it has made in the person's life is remarkable.

In 2001, the Administration on Developmental Disabilities awarded Inclusion Research Institute (IRI) a grant to promote the SDSC model throughout the United States (<u>www.self-determined.org</u>). IRI has been tracking the establishment of the SDSC's and Microboard approach over the past two years. Currently there are approximately 55 SDSC's/Microboards across the United States and the numbers are growing rapidly. States that have these small boards already established are: Maryland, Colorado, Oregon, Missouri, Utah, Oklahoma, Virginia, Pennsylvania, Arizona and Tennessee.

I believe that you learn more through an example rather than simply sharing a philosophy, so perhaps you may learn more about the SDSC from reading about my own son, Joshua.

What A Difference a SDSC Can Make: Joshua's House Incorporated! By Jackie Golden

Joshua's House Incorporated (JHI) is much more than a name of a corporation. It is my son's, Joshua Golden, lifeline. JHI is a Self-directed Support Corporation (SDSC) that was designed to deliver the supports Joshua needs to live successfully and fully included into his community. Simple put JHI is a provider agency, but doesn't provide services to 500 people, it provides custom designed supports for only one person, Joshua. For Joshua and his family JHI delivers his supports using the principles and tools of self-determination but more importantly for Joshua it delivers freedom!

Joshua Golden is a survivor of our (traditional) support networks. By this I mean that our system has provided some type of supports since Joshua was 8 years old. These supports never matched Joshua's needs and often hurt Joshua (physically and mentally). We explored the SDSC model and often wondered, "Why can't we become the provider?" We knew that the government needed their accountability, but Joshua needed control over his supports and our systems were taking too long to catch up with Joshua's needs, so the SDSC was the answer.

How does it work? We have formed a not for profit, JHI, around Joshua and became the legal entity to receive Joshua's allotted Medicaid dollars, as his agency. Only people who care and share a vision for Joshua serve (on a volunteer basis) on his board of directors. The board, committed to Joshua, assures Joshua receives services that match his needs, desires and lifestyle. He is in control, with the assistance of people that want him to be successful.

What does this mean for Joshua? It means that Joshua no longer has to deal with a system that doesn't value him as a person. He can select who comes into his life as his support team he is the director and decision maker, balanced with others that care about him. By now you are thinking that Joshua is a very able young man. That is true and if you met Joshua you would realize that Joshua needs 24 hours a day, seven days a week care and he has significant cognitive disabilities. It is support team, JHI and his staff, who recognize that Joshua is at his best when his life is filled with people that care and want him to succeed. Joshua directs JHI. For Joshua it means FREEDOM.

What does this mean for Joshua's family? Joshua's sister and his parents serve on his board, along with Joshua. The board also has 5 other board members, so Mom can be out voted (as it should be), as it is Joshua's life. The key is to have people with that vision, and commitment who are willing to spend time with Joshua. It also means a support network for Joshua's family. No longer is it only his parents looking to secure Joshua's future. It is his legal board of directors that are working for him. For Joshua's sister, she now realizes that she will have people to help her with Joshua when his parents are no longer around, it is a support team for her as well.

We have been asked what it is like to have such an agency for Joshua? Our response is, while it is work, it is the most wonderful thing that has happened to Joshua and us. He truly can have a life that is his own and we can finally sleep at night, knowing that there are only people that care about him in his life. Joshua does not speak, or at least not in a

verbal response. But one look at that terrific smile of his and seeing him relaxed and loving life, says it is worth every minute of establishment of a SDSC. He is finally free.