

# Parents and Self-Determination

## *From One Parent to Another*

In a system built around self-determination, the individual with a disability plays the lead role but they also must and do rely on others, including their parents. There seems to be a misconception that in a self-determined environment parents are excluded. That is simply not true. Parents have supported and advocated for their children who have disabilities for years and that support and expertise continue to be invaluable. Adult children with disabilities, like all adult children, will likely continue to want the support of their parents. In fact, if you ask individuals with disabilities: "What or who most enables and supports you to be self-determined?", they answer:

"My parents."

But if you then ask them: "What or who most prevents you from being self-determined?" they answer:

"My parents."

Parents may fulfill many roles in a self-determined environment: advocate, care provider, home provider, member of support circle, participant in person-centered planning, and most importantly – parent. There is an adjustment for both the parent and the child when any young person grows up and leaves home. The degree to which a parent is involved in the life of their adult child with a disability is really up to that child and parent. Just like any other adult child. Nobody is 'mandating' the exclusion of parents. That is not what self-determination is about.

Self-determination means that an individual is actively involved in making decisions about his/her life and needed services and supports. It means that a service system will be more flexible and be able to respond to those needs in a way that is desired by the individual. It means that a person with a disability would be able to hire whom they want to receive the specific services they want in the way that they want to receive them. It is just more flexible all around.

This system infrastructure is built around enabling and supporting an individual to make informed decisions. Informed decisions are enabled when an individual and their support circle (including parents) have the information they need to make decisions about what services and supports look like for them. It contains the pieces necessary to support a person-centered decision-making and planning process. This process requires the involvement of the key people in the person's life. In nearly all cases, we would expect that to include parents and other family members.

Parents have asked: "Who defines if a person can self-determine and at what level?" Nobody is going to 'define' a person. If a person wants to make decisions about their daily life, activities, services – no matter how small those decisions may seem – they are acting in a self-determined way. How the people around them support those decisions and choices is key to the enhancement of the quality of life of that individual.

Another question that often comes up is "How does a person who has a severe cognitive disability or who is unable to communicate take part in self-determination?" No one will deny that individuals with multiple and/or severe disabilities probably need a different array of supports than someone with less significant needs. The key is that the needed

supports must be put in place for persons with cognitive disabilities throughout the decision-making and planning process. People who understand how that person communicates, what their preferences are and what kind of life they would like to live can help to support that person and facilitate their communication to ensure that their preferences are honored. Families especially, may play a role in communicating these wishes, hopes and dreams. Self-determination does not propose to 'hang people out there on their own.' People will need continued support to live a self-determined life. The reality of life is that we are all interdependent on each other. We all need support.

A self-directed system strives for a balance of independence and risk, of helping people make informed choices while assuring basic safety. We all learn by some of the mistakes we make. So it is with people with developmental disabilities who want to have more control over their lives. Some risks are acceptable, some are not and some fall in that gray area in between. The successful management of those risks is enhanced by surrounding the person with a caring and knowledgeable circle of support who helps the person understand the benefits and consequences of the decisions they are making, and then who let go and allow the person to take those risks that increase independence and responsibility, not those that threaten health and safety. Individual service plans must include risk management components that include information about: who makes decisions and when, how emergencies are handled and specific back-up systems defined.

Many parents have worked hard, in spite of the "system" to build an individualized array of supports for their child. Sometimes it has felt like a house of cards that would collapse when one of the care providers got sick or went on vacation, or when the state changed reimbursement rates for providers. Trust was slow to come and may still not be there. And now, another option is being developed that may threaten to topple this delicately balanced system. In response, parents have questions about how they can trust this new system. Will the services and supports be in place over time? Will they threaten what they currently have?

First, lets acknowledge that there are no guarantees regarding the future of services – not the ones we have now or ones that are proposed. What we can say is that the Council, in advocating the self-determination model, recognized that for many families there is a desire to maintain (or improve) what they currently have. They may not be ready to have their family member direct his/her own services, or even know how that will work. That is why the option that has recently become available is just that – an option. People do not have to choose to self-direct their services, they can continue to use traditional waiver services. It is voluntary, not mandatory. It is an optional way of receiving Medicaid waiver services for those who are or who will be eligible for the current developmental disability waiver.

Some parents have asked about the availability of supports in rural areas. If you currently are confined to purchasing a certain package of services through an agency and there is no agency in your local community, a self-determined system would enable you to purchase the services and supports you need from an individual that you choose – a non-traditional provider - at the time that you need the service or support and in the way that you prefer. One positive aspect of a self-directed service system is that the person has more flexibility in designing his/her supports. This can make supports and services more accessible in a rural area than they may be now. For example: if an individual needs and wants support in doing their grocery shopping and errands in their community, that individual would be able to hire someone from their community to help them to do those things. It's called Community Supports and if the service desired meets the definition, it could be reimbursed by Medicaid under this self-determination waiver.

Another question about rural areas has been “Who will be in a person’s support circle?” The answer is whoever the individual wants to be in their support circle. It could be friends, co-workers, parents, siblings, classmates, neighbors, community members, support staff, service providers. Anyone that a person feels understands them, their preferences for the kind of life they want to live and who will support their choices and goals.

It can be confusing with so much varied terminology being tossed around: self-determination, self-directed supports, participant-driven services. Some people have asked what “the Money Follows the Person” really means. This is terminology being used at the federal level as an umbrella for many different systems change and quality initiatives. To read more about this you can visit the CMS website at:

<http://www.cms.hhs.gov/NewFreedomInitiative/>

Questions about personal assets, trusts, etc. that are very specific to individual families cannot be answered here through a description of a self-directed service system. Those questions require individual responses unique to those specific circumstances.

For the last several years, Centers for Medicare and Medicaid Services (CMS) has been encouraging states to change their service systems, moving towards a more self-directed, participant-driven approach. Our own Department of Health and Welfare and state Medicaid agency has been making steps in that direction with improvements to the service system design in Idaho. This is a gradual process, one that aims to serve people better and provide more choice for individuals and their families in how they receive services.

In 2003, the Task Force on Self Determination Waiver Group was formed to work on a self-directed service system model development, to take the principles and mission developed by the original Task Force in 2001 and organize them into a format that would meet the requirements of an Independence Plus waiver. The following are components of that waiver template:

- Individual budgets that are driven by the plan of service
- Person centered planning that is outcome driven
- Fiscal intermediaries who operate like an accounting service, paying the providers of service and billing Medicaid for reimbursement
- Personal brokers that work for the individual and, among other things, help the person negotiate for the services they want and need
- The ability to purchase services from other than traditional Medicaid providers
- Quality assurance that is integral to the entire process from plan development to service delivery to customer satisfaction and goal achievement

From the beginning, the Task Force included individuals with disabilities, parents, service providers, state agency representatives, and other disability organization representatives. We have made every attempt to make this a very collaborative project, with information available to Task Force members and others to share with their constituencies all along. Task Force members have a wealth of information about key system components under consideration and development. We are currently working on a document that compares the current service system to a self-directed model in a more direct way.

The Task Force completed its work on the design of a self-directed service system and Medicaid continued to work on the model with a plan for implementation that Idaho

submitted to the CMS in Washington DC. That plan was approved and Idaho has now begun a pilot project in just three areas of the state. The reason to start small is so that changes can be made if we discover problems we had not anticipated and people who are self-directing their services find success in unique and creative ways.

We don't have all the answers at this time. Self-determination and self-directed supports service systems are fairly young. Much of what has been learned on a national basis comes from the Robert Wood Johnson Self Determination Initiative demonstration projects. A final assessment report of the projects, plus additional information, is available through the internet on the Human Services Research Institute (HSRI) website at: [www.hsri.org](http://www.hsri.org) - under publications and self-determination. Many states are currently implementing self-directed service programs and many of them are years ahead of Idaho. Some of the things we are hearing include:

- People have greater satisfaction with their services and supports.
- Services and supports meet their needs better.
- People do not have to buy services that they don't want to get the services they do want and need
- Risk is no greater for the person than in a traditional system

Many parents see self-determination as an important part of their child's life for many different reasons. Often parents ask: "What happens after I die? Will my child have the supports and services they need to live the life they want to live?" Helping a child/adult to develop their communication skills, teaching them how to make informed decisions, building in them an expectation that their preferences will be honored, and helping them learn how to advocate for themselves is what will make the difference. This is what self-determination is all about.

After we are gone our children will need to be able to speak for themselves and expect that others will listen. Children and adults with extensive support needs also need to be supported to find ways to communicate their preferences. It is important to build circles of support around these individuals that include people who understand the individual, how they communicate and will honor their preferences and the life that they want for themselves. It is never too early to begin to form this circle of support. It is best when these circles include a wide array of individuals: family members, friends, classmates, co-workers, community members, etc. so that there is support coming from a variety of sources.

The ultimate goal of the Self Determination Task Force is that people with developmental disabilities in Idaho will have the opportunity to live a life like anyone else. This includes being in control of their life and living in communities like anyone else.

The main issues being addressed by the task force include:

- Individualized budgets are allocated fairly and will, in aggregate, be cost neutral.
- Associated risks will be managed to assure health and well being of individuals and system accountability.
- Supports will be provided to participants so that service planning and delivery is undertaken efficiently and with desired outcomes.
- Promotion of the participation and support of families and others in the community.

- Supported development over time of an increasingly agile and responsive provider network.

The Task Force intends to move ahead steadily, but not recklessly, to create change in our service system, political system and in our communities that is consistent with self-determination principles. We look forward to parents being involved as participants in this discussion and planning process that places its emphasis on meeting the needs of individuals with developmental disabilities and encouraging them, their loved ones and their communities to embrace the idea of choice and self-determination.

UPDATE: As of March 2007, the My Voice My Choice Medicaid service option is available to adults with developmental disabilities in the Moscow, Boise and Pocatello areas. Starting in just these three areas gives us the opportunity to focus on success for individuals who are the first to sign up for the option and address any systems problems that are identified before the option is made available statewide.