

# **Speak Up! Guide**

## **5: Self-Advocacy and Self-Determination**

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For further information please call Rebekah Pennell at (919) 966-5171.

# Speak Up! Guide

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## SELF-ADVOCACY DEFINED...

Self-advocacy is having the opportunity to know your rights and responsibilities stand up for them, and make choices about your own life. Self-advocacy allows people with disabilities to **speak out for themselves**. By doing these things, the quality of life for people with disabilities is vastly improved.

The self-advocacy movement began in Sweden in the 1960's when a group of people with mental retardation drew up a list of requests about how they wanted services delivered and what they wanted from their service providers. Back then; what these pioneers did was a novel idea, but not any more. Now, this idea has taken the shape of an international civil rights movement by and for people with developmental disabilities.

The self-advocacy movement is closely related to the self-determination movement. The self-advocacy movement emphasizes self-advocates speaking out for themselves and learning about their rights and responsibilities. The self-determination movement also does these things, plus it focuses on the important components of system changes, legislation, policy, etc.

## RESOURCES FOR FINDING OUT MORE ABOUT SELF-ADVOCACY...

- ◆ <http://www.self-advocate.org>
- ◆ <http://web.syr.edu/~thechp/moretho.htm>
- ◆ <http://www.customcpu.com/np/alaskapf/default.htm>
- ◆ <http://thearc.org/misc/sadescr.html>
- ◆ [http://cnet.unb.ca/cap/partners/chsptf/bc\\_advocacy.html](http://cnet.unb.ca/cap/partners/chsptf/bc_advocacy.html)
- ◆ <http://www.wf.net/~thearc/people.html>
- ◆ [http://www.villagelife.org/news/archives/11-4-97\\_selfadvocacy.html](http://www.villagelife.org/news/archives/11-4-97_selfadvocacy.html)
- ◆ <http://web.syr.edu/~thechp/samoveta.htm>
- ◆ <http://thearc.org/posits/selfadv.html>
- ◆ <http://thearac.org/misc/sabib.html>
- ◆ <http://www.ohsu.edu/selfdetermination/proclamation.shtml>
- ◆ <http://www.nami.org/youth/selfadv.htm>
- ◆ [http://cnet.unb.ca/cap/partners/chsptf/bc\\_advocacy.html](http://cnet.unb.ca/cap/partners/chsptf/bc_advocacy.html)
- ◆ <http://www.people1st.net/>

## **SELF-ADVOCACY: WHAT IT IS...**

### *SELF-ADVOCACY IS...*

People speaking-up for the things that they see as important for themselves

Informed individuals expressing themselves

Something everyone is capable of

Here to stay, Change

A Revolution

People taking control over their own lives...for their decisions and also for the consequences

A process

A way of life

An inclusive, ALL encompassing, on-going learning experience for everyone involved

Creating a new "System" (we won't do it the same anymore...the "old way" stunk!)

Acknowledging anger and working it through

The means...a tool or vehicle for change

Learning to trust

Taking risks

Going after your dreams

Making mistakes...and learning from them

Asking questions

## **...WHAT IT ISN'T**

### *SELF-ADVOCACY IS NOT...*

People sitting around and complaining

A token way for an agency to say that it "includes" the people it offers services to

Only for a select group

A fad

Stagnation

A Revolt

A program for John to make an independent choice for 3 out of 4 consecutive trials of success

A product

An activity

A skills training class to meet a GSP goal

Turning "The System" upside down (i.e.: "we'll do to them what they've always done to us!")

Staying angry

The end

Living in fear

Passive

Living in a padded room

Sleeping through your dreams (or having a recurring nightmare!)

Playing it safe

Being questioned

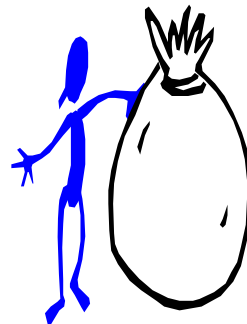
## SACK OF DREAMS

What is **one** of your future goals (one dream)?

- ❖ Put your face and your dream on the outside of a paper sack
- ❖ Write and or use index cards to draw some answers to these questions. Put them in the sack:

- 1) What are your strengths? What are you good at?
  
- 2) Who are some friends you know will be able to help you reach your dream?
  
- 3) Who do you get support from (an agency and/or staff people)?
  
- 4) What are your “resources” – i.e.: how much of a budget do you have?
  
- 5) What is available in the community? (Groups you could connect with, free things that agencies might offer, public meetings, special classes, etc., etc.)

As questions arise about making your dream come true, think about how you can answer them with the resources in your sack.



## AN “ABOUT ME” BOX

Have you ever been frustrated because you wanted to say something, tell a friend about your recent vacation, or describe how you felt when you heard a new song, but you couldn't put it all into words? This activity will help.

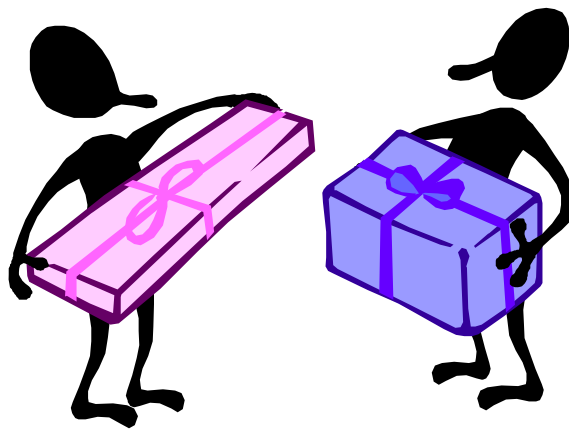
Someone once said that a picture is worth a thousand words. For this exercise, you will use pictures, objects, and other things to tell people about yourself. Follow the steps below.

### (1) MAKE YOUR BOX:

Decorate the container of your choice in a way that tells others something about you. Be creative! You can use different containers (a plant pot, a Kentucky Fried Chicken Bucket, a beach bucket, a shoe box with comic strips on it, etc.).

### (2) FILL YOUR BOX:

Pick different things that answer the questions below. These can include objects, pictures, music, food, aromas, things that have a certain texture, things that feel a certain way, like sand paper being scratchy and cotton being soft, and more!



## QUESTIONS TO ANSWER:

Use this sheet to take notes on your answers if you need to.  
Get a friend to help you write things down if you want – or you can draw pictures!

(1) Who is your family?

(2) Who are your friends?

(3) Where do you spend your time during the day (work, volunteer, at home, etc.)?

(4) Where do you live?

(5) What is one thing you are good at – or one thing you are proud you have done?

(6) What do you dream about doing / want to do one day??

***REMEMBER: THERE ARE NO WRONG ANSWERS!!!***



# CHEAT SHEET!!

## Confused?? Here are some examples to help

- a family photo “talks” about your family
- a card from a friend “talks” about your friend
- a coffee mug from the restaurant where you work “talks” about your job
- a house key “talks” about your apartment
- a trophy, medal or newspaper story written about you “talks” about something you’re proud of
- a bag of play money “talks” about your dream of getting a good job one day that pays well

Thanks to the following people for helping develop “About Me Boxes”:  
Lynda Kahn, Deb Griffin Knew, Jo Krippenstapel, Tim LaFazia,  
Doreen McConaghy, Angela Semonelli & Carol Wilson

## **SELF-DETERMINATION DEFINED...**

Ultimately, self-determination means that people with disabilities will be in charge of their own services and in control of money to make their desires and dreams real. Self-determination involves people with disabilities claiming their basic civil rights including all of the freedoms guaranteed by our Constitution and Bill of Rights. Self-determination is the freedom to make individual choices about one's own life and the opportunity to fail, just like any other person. In order to achieve these goals, there will have to be major changes in social attitudes and policy. Self-determination is going to require a lot of very hard work and a collaborative effort among *all* people with disabilities and advocacy groups.

Some thoughts from Ellen Cummings (a national consultant on Self-Determination)... "One of the most important things about self-determination is its power shift. Self-determination without the ability to control the resources is fantasy, and that's what makes self-determination different from anything else we have done." Self-determination means that people have authority over how, where, and with whom their lives will be lived. It means that people have control of the resources needed for their support and responsibility for their decisions and actions.

Self-determination refers to "acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference" (Wehmeyer, 1994).

## RESOURCES FOR FINDING OUT MORE ABOUT SELF-DETERMINATION...

- ◆ <http://www.self-advocate.org>
- ◆ <http://www.self-determination.org/>
- ◆ <http://www.rwjf.org/>
- ◆ <http://www.uncc.edu/sdsp/>
- ◆ <http://www.libertynet.org/>
- ◆ <http://www.pbrookes.com>
- ◆ <http://www.iod.unh.edu/projects/rwj.htm>
- ◆ <http://www.ohsu/selfdetermination/index.shtml>
- ◆ <http://www.ohsu.edu/selfdetermination/natcent.shtml>
- ◆ <http://www.napanet.net/business/personal/ASA/selfdetermine.html>
- ◆ <http://www.mcare.net/overview.html>
- ◆ <http://www.mcare.net/beyond.html>
- ◆ <http://www.thearc.org>
- ◆ <http://www.rfgeen.com/sdsp/right.htm>
- ◆ <http://www.state.nh.us/sdp/princ.html>
- ◆ <http://www.vcu.edu/rrtcweb/sec/feb5.html>
- ◆ [http://www.libertynet.org/speakng/learning\\_p.html](http://www.libertynet.org/speakng/learning_p.html)
- ◆ <http://www.ohsu.edu/selfdetermination/selfdet.shtml>
- ◆ <http://www.ohsu.edu/selfdetermination/alliance.shtml>
- ◆ <http://www.aamr.org/ShapingOurDestiny/ProviderGuide.html>

## WHAT IS SELF-DETERMINATION?

Self-Determination: what a complex word to explain such a basic concept.

Across the country, the idea of self-determination is changing the way people with developmental disabilities live their lives. It also spells change for how public services are designed and delivered to meet these individuals' needs. In North Carolina, four projects are demonstrating how this idea can be put to work to change people's lives. Meanwhile interest is growing across the state among self-advocates and parents to make self-determination work statewide.

It can be as simple as being able to choose extra sauce on your pizza or as complex as choosing to live in your own apartment with the services and supports you need.

Self-determination simply is the freedom and right to make choices about one's life, the same choices that people without disabilities take for granted. People with disabilities deserve the right to determine what services and supports they need, and who will provide them. How and when they use their resources are decisions that people with disabilities should have the power to make.

The constitution of the United States guarantees to all citizens: the right to life, liberty and the pursuit of happiness. Without self-determination those rights are taken away.

Today self-determination is just a dream for most people with disabilities. Decisions are made for them; where and with whom they will live, where and when they will work, when to get up and when to go to bed, what time of day to take their shower or bath are usually the decisions someone makes for them. When you are part of a group the groups needs come before the individual's.

Sheltered workshops and group homes were considered innovative ideas in their time, however today they are outdated and provide little or no opportunity for individuals to fulfill their dreams for life. How long could you work in the same room or building with little or no access to the real world? Would you be happy performing the same job day after day? Could you enjoy a job that you did not choose, but one that the system chose for you?

How would you like to live in a home with a group of people you did not choose to live with, or eat from a menu that was prepared by a stranger who did not take into consideration your likes and dislikes? Do you really think that people who live in-group homes all want to go see the same movie or all want to go bowling on the third Saturday of the month? If given the opportunity to decide what they would like to do, each one might have a different idea of what would be fun to do that day.

We seem to have a great misconception that if someone does not look like us, they are somehow different. That idea is far from the truth. A person's ability to walk does not affect their ability to think. Many people who have physical limitations when given the chance to learn and communicate their dreams successfully fulfill those dreams. They are able to work in the community, attend social functions, and receive an education to the best of their abilities.

Citizens with limited cognitive abilities also have dreams the same as you and I. They want to live in a loving, supportive, family environment. They deserve the right to work at a job that they enjoy and chose, not a job that was picked for them. Even taking part in deciding where they would like to go for a vacation is self-determination.

There is an ever-growing cry from people with disabilities and their families to gain the control of their lives that we take for granted. People with disabilities need and want to be contributing members of our communities.

No one is independent of others. We are all interdependent. Utility companies provide our electricity, water, and phone services. The media provides us the news. We rely on farmers to grow the food we eat and sanitary workers to take away our leftover trash. We rely on friends and family in times of crisis. Our neighbors come to our aid when they see we are in need of help.

Every one of us has different abilities and interests. Some of us require help in accomplishing daily tasks that others take for granted. People with disabilities are part of our system already, and contribute a great deal to our lives through their participation in our work places, communities, and families. More individuals want that chance!

We all have dreams for our future. People with disabilities have those same dreams and are willing to work towards their goals just like you and I. Yes people young or old with disabilities do want control of their lives.

Self-Determination is just a simple concept, the basic right to fulfill one's dream for their future. Please help us make it a reality for all people.

Written By  
Rosemary Livingston Bernauer  
For my son Andrew and people with disabilities everywhere

# FACT SHEET: SUMMARY OF SELF-DETERMINATION

## *What Self-Determination Is and What it Is Not*

- ☀ Self-Determination is NOT a model or a program with a predetermined menu of available services and a set way of delivering them.
- ☀ Self-Determination IS a process that differs from person to person according to what each individual determines is necessary and desirable to create a satisfying and personally meaningful life. Persons with disabilities no longer have to receive services as determined by the traditional model. They are free to “order off the menu,” including those services they desire to be provided in ways that meet their needs.
- ☀ Self-Determination is both person-centered and person-directed. It acknowledges the rights of people with disabilities to take charge of and responsibility for their lives. In Self-Determination, the individual, not the service system, decides where he or she will live, and with whom; what type of services he or she requires, and who will provide them; how he or she will spend his or her time, which may include the type of vocational or educational opportunities he or she wishes to engage in, and how he or she will relate to the community, which may include joining in community events, taking part in civic groups, and developing and maintaining relationships with others in the community.

## *The Principles of Self-Determination*

- ★ Freedom – The ability for an individual together with freely chosen family and friends to plan a life with necessary support rather than purchase a program.
- ★ Authority – The ability for a person with a disability (with a social support network or circle if needed) to control a certain sum of dollars in order to purchase services.
- ★ Autonomy – The arranging of resources and personnel—both formal and informal—that will assist an individual with a disability to live a life in the community rich in community affiliations.
- ★ Responsibility – The acceptance of a valued role in a person’s community through competitive employment, organizational affiliations, spiritual development, and general caring of others in the community, as well as accountability for spending public dollars in ways that are life enhancing for persons with disabilities.

# PRINCIPLES OF SELF-DETERMINATION

People with developmental disabilities have:

## **FREEDOM**

### **The *freedom* to develop a personal life plan.**

People with developmental disabilities have the freedom to make life decisions. Self-Determination recognizes that this is an ongoing and dynamic process. The work of those committed to persons with disabilities is to assist the individual when she or he needs assistance in exercising this right.

### ***THIS MEANS***

You must plan your own life. Your plans must fit your budget. If you want to change your plan, you can do it. You can do the things you want to do, but you must know what you want to do and when you want to do it.

Different people make different choices. Some people choose to have an apartment of their own. Others choose roommates. Some buy houses or condos to live in. Other people get married and find their own apartment. Some people get vans and adapt them for their disability. People can shop where they like. They can buy and wear their style of clothes. They can buy the food they enjoy and go out to eat when they want as long as it all fits in their budget. They can find a good job, and hire the people they like to help them when they need help.

## **AUTHORITY**

### **The *authority* to control a targeted amount of resources.**

The resources are under the control of the individual and freely chosen family members and friends. This means that the resources are portable. They can be re-configured; priorities can be changed and the dollars follow the individual as his or her priorities change. Public dollars are used wisely to buy supports and services the person wants and needs.

### ***THIS MEANS***

Every person will have their own special government money account. People who need a lot of help will get more money than people who only need a little help. An agency acts like a bank. You can change agencies if you want to. When you need money to pay someone who works for you, you and your circle of support tell your agency who they should pay and how much they get. The agency will pay for all the expenses you budget for such as programs, transportation, community activities, schools and maybe rent.

## **SUPPORT**

### **The *support* needed to obtain personal goals.**

Those supporting individuals with disabilities also must be free to provide the desired assistance, either as employees of service agencies or when hired by the individual, to achieve the variety and intensity of supports an individual may desire.

### ***THIS MEANS***

You will have to find a group of family, friends, community members, and professionals

to help you decide what supports you need to live responsibly in the community. You will decide, but other people who you trust will help you think about it. This group is called your **circle of support**.

You can hire your own staff, people you like to help you, either from an agency or someone you know and trust in your neighborhood. If you need a lot of help, you may want to hire someone who spends the night with you or lives with you. If you need less help, perhaps people can come a few hours a day. They can help you with your medication. You can hire people who are good at math to help you with the bills, or a good cook to teach you how to cook. An aide could help you with dressing and cleaning if you can't do that yourself. You can hire someone to help you find the job you want. You must plan on enough supports to keep you safe and healthy. It all depends on what you need and want.

### **DO YOU WANT TO BE IN SELF-DETERMINATION?**

Do you like where you are living now, or do you want to live somewhere else? Do you have a job? One that you like? Do you earn some money? Do you get to go to places you like to go? Can you and your friends get together when you want to?

Self-Determination can help you to answer these questions with a **big YES!**

### **HOW DOES SELF-DETERMINATION WORK?**

People that choose the Self-Determination process may have an agency helping them. If they live in an agency house, they will have to follow the agency rules. If they rent or own their own place, they make their own decisions.

You need a plan for your life. A service coordinator or a service broker can be paid to help you develop your plan. They can also help you put your plan into action. You need to find your family, friends, community friends and staff people who are willing to become part of your **circle of support** to help you.

You need to find out more about Self-Determination. Call your Self-Advocacy Association or your DDSO.

### **RESPONSIBILITY**

**The *responsibility* for contributing to one's community and using public dollars wisely.**

They have the ordinary obligations associated with freedom in America. These are obligations of citizenship and include the obligation to spend public dollars in ways that are life-enhancing and cost-effective. This obligation includes engaging other social, business, and religious organizations in ways that help redefine and build community for all of us. The individual also has the responsibility to give back to the community through paid and volunteer work whenever possible. This includes seeking jobs in the community, and using supports to find and keep employment.

### ***THIS MEANS***

Earning your own money is important. You should try to find a way to get a paying job. You can use some of your government money to help you do this. Money that comes from the government has to be spent according to certain rules. You will have to spend your government money that the agency takes care of wisely. You can spend money you earn on the things you want. Of course, you will have to pay for your food and rent first.



You will also want to make more friends in the community. One of the best ways of doing this is to belong to clubs, churches and service organizations like the “Y”, the Moose, the Lions or other fine organizations. You can find ways to help them with their projects in your free time.

## VALUES SUPPORTED BY SELF-DETERMINATION

⇒ **Respect** – Self-Determination, by its nature, recognizes that persons with disabilities are valuable, capable persons who deserve to be treated with respect. Respect is more than politeness and paying lip service. It is acknowledging the individual's value as a person, seeing his or her strengths and abilities, granting him or her the same consideration we each desire, and holding him and her in esteem.

⇒ **Choice** – Choice is central to Self-Determination. Many times people with disabilities have very limited choices. They often cannot choose very important aspects of their lives, such as where they live, with whom, how they will spend their time and their money, and sometimes even what they eat. At other times, selections are limited. For instance, individuals may be able to choose who their roommate will be, but not whether or not they will have one. True choice is being able to pick from the same wide variety of lifestyles, goals, and individual preferences most people enjoy.

⇒ **Ownership** – Self-Determination not only supports persons with disabilities to have more choices in their lives, but ownership of their lives. Ownership implies more than just decision-making. It means that the individual is the final and total authority—the boss. While most people are supported in the decision-making process by a circle of support, Self-Determination gives the person the final say. Ownership allows him or her control over his or her life and services. He or she may hire, manage, and if necessary, fire those who provide services. It also gives him or her control over the management of his or her financial affairs. Ownership also means that the individual accepts the responsibility for his or her actions and decisions, including spending public monies conservatively.

⇒ **Support** – Support is a keystone to making Self-Determination work. Most people have some type of support network in their lives that they turn to when they must make an important decision or take a step forward in their lives. Persons with disabilities are no different. However, before Self-Determination, those persons who helped establish goals and devise plans were mostly paid workers who in many instances were assigned rather than chosen. In Self-Determination the individual selects and invites each member of his or her circle of support. They can be family members, friends, and people from the community—anyone that the person desires. Most importantly, they are people with whom the individual has or wishes to build a trusting relationship.

⇒ **Opportunity** – Many persons with disabilities have had only limited opportunities to experience many aspects of life. Self-Determination expands those opportunities allowing and encouraging individuals to explore the possibilities that are present in their communities. Since they are able to spend their funds in ways that they now choose, they are able to take part in events and activities that previously were unavailable. When someone has had limited experience, it may be difficult for others to allow him or her to take risks. However, opportunity also includes the ability to take risks, to make mistakes, and to grow from them.

### ***Self-Determination Calls for a Systems Shift***

If Self-Determination is going to be successful, it requires that those who supply services and fund them make certain changes in both the way they think about persons with disabilities and the way they serve them. Without a shift in the service system, no philosophy can truly support persons with disabilities to become self-determining individuals. In order for Self-Determination to happen, the system must shift:

- From seeing persons with disabilities as having limitations that prevent them from participating fully

in life to seeing them as valuable citizens who have many talents, strengths, and abilities to contribute to their communities.

- From seeing persons with disabilities as service recipients to seeing them as individuals with rights and entitlements.
- From providing agency-controlled services to supporting person-directed services.
- From systemic and agency control of financial resources to individual control.
- From control to empowerment.

### *A Final Thought*

“Self-Determination is what life is all about. Without it, you might be alive, but you wouldn’t be living—you would just be existing”

(M. Kennedy, “Self-Determination and Trust: My Experiences and Thoughts,” In Sands & Wehmeyer, *Self-Determination Across the Life Span*, 1996, p. 48).

Prepared by Michael Kennedy & Lori Lewin, Staff Associates

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#### NRC FACT SHEET

National Resource Center on Supported Living and Choice, Center on Human Policy Syracuse University, 805 South Crouse Avenue, Syracuse, NY 13244-22801-800-894-0826 ( 315-443-3851 (voice) ( 315-443-4355 (tty) ( 315-443-4338 (fax) <http://soeweb.syr.edu/thechp> ( [thechp@sued.syr.edu](mailto:thechp@sued.syr.edu)

# MACROW

## SELF-DETERMINATION CHECKLIST

VERSION 3.3  
(Revised 3.12.01)

Developed to Assist Self-Advocates, Family Members, Personal Agents, Case Managers, Support Coordinators, Service Coordinators, Support Brokers, Fiscal Intermediaries and Circle Members in Developing Person Centered Plans and Individual Budgets  
Based on the Principles of Self-Determination

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**Ric Crowley**  
**30803 Dunn Rd.**  
**Denham Springs, LA 70726**  
**225-939-0344 (voice)**  
**225-667-4040 (home office)**  
**225-667-3512 (fax)**  
**macrownet@aol.com**

**Bob McCaffrey**  
**415 Breakfast Hill Rd.**  
**Greenland, NH 03840**  
**603-479-0791 (home office & fax)**  
**603-512-1850 (voice)**  
**BOBZACMAC@aol.com**

## **PREFACE**

This checklist is intended to be a barometer to indicate if you are setting a course that will ultimately support individuals with disabilities in “getting a life.” Many individuals have, through conversation, presentations, publications or sharing life experiences contributed to this checklist. Periodically it will be revised to incorporate current feelings, needs, dreams and views of individuals with disabilities, their families and friends. The checklist is not intended to replace or be used as a personal "outcomes" evaluation tool.

The reference to the "Personal Life Quality Protocol" (Center for Outcome Analysis) and the "Planning Guide for Paid and Unpaid Companions" (Cummings and Crowley) are suggestions only. Other tools serving the same purpose may be available. The Principles of Self- Determination and Principles for Action are provided as reminders to those completing the checklist.

[NOTE: The following pages are adapted from several publications authored by Ellen Cummings, Thomas Nerney, James W. Conroy, Anita Yuskauskas, Robert P. McCaffrey and Richard F. Crowley.]

## **DEFINITION OF SELF-DETERMINATION**

“A national movement to redesign long-term care for individuals with disabilities that eschews the traditional program models and facility placement approaches ...Self-determination insists that public dollars be seen as an investment in the lives of people with disabilities. Public dollars need to be used strategically to support existing family and community relationships as well as to help create them where they do not exist.”

Tom Nerney, 1998

## PRINCIPLES OF SELF-DETERMINATION

The following principles are meant to provide a philosophical foundation for substantive system and cultural change that incorporates values deeply held by persons with disabilities, families, friends and advocates:

- FREEDOM:** to choose a meaningful life in the community
- AUTHORITY:** over a targeted amount of dollars
- SUPPORT:** to organize resources in ways that are life enhancing and meaningful to the individual with a disability;
- RESPONSIBILITY:** for the wise use of public dollars and recognition of the contribution individuals with disabilities can make to their communities
- AFFIRMATION:** of the important leadership role that self advocates must play in a redesigned system and support for the self advocacy movement

## PRINCIPLES FOR ACTION

**Self-Determination is another way of saying *freedom*. It is a fundamental human right that *affirms* the leadership roll self advocates and family members and empowers people to have *authority* over how their lives will be lived, where and with whom. It means that people have control of the resources needed for their *support*, as well as having *responsibility* for their decisions and actions. It *affirms* the emerging leadership role that self-advocates and family members have in guiding systems change.**

### **DIGNITY AND RESPECT**

All people have an inherent right to be treated with dignity and to be respected as a whole person with regard to mind, body, and spirit. Most of life's greatest lessons are learned when we make choices that we later realize were mistakes. All people have the right to the dignity of risk. The network of support makes risk possible by weaving a net, which provides safety and supports growth.

### **RELATIONSHIPS**

Supporting people in developing and maintaining relationships is an on-going process. A relationship must be treasured, nurtured and protected. Those with whom the individual has real relationships provide the strength assistance and security, which ensure each person's well being.

### **CHOICE**

People have a right to choose what they do with their lives where and with whom. When people need help, it is friends and family closest to them who can assist in broadening their experiences and exercising their right to choose. A personal network or circle of support chosen by the person ensures freedom of choice.

### **CONTROL**

People have the power to make decisions and truly control their lives, including their resources and finances. If support must be purchased, the people buying it, with assistance from family and friends when necessary will determine which supports will be purchased and when. People must have control of hiring those who will provide support.

### **DREAMING**

All people have dreams and aspirations that guide the actions that are most meaningful to them including commitment to helping people create their dreams, respecting those dreams and helping make them come true is crucial.

### **CONTRIBUTION AND COMMUNITY**

Everyone has the ability to contribute to his or her community in a meaningful way. Giving of ourselves helps us establish a sense of belonging and identity. Community membership includes having the opportunity to be truly involved in the routines of the community and to make a difference in the lives of others.

## ❑ FISCAL CONSERVATISM

The services the present systems provide are often expensive and often do not meet the needs of those they are intended to support. Making things happen does not always require money. If people have, opportunities to make real choices, and control over those choices, they will purchase support in a way that will allow them to get what they need, and pay only for what they receive. Make real investments, spend money more efficiently and make adjustments when needed. They are also responsible to contribute to their support from all financial resources at their disposal. To find the best quality for the most reasonable price, people must be free to purchase in and out of the system.

## ❑ CHANGING ROLES OF PROFESSIONALS

Individuals, as they take control authority over their lives and resources, will assume responsibility for their decisions and actions. Professional and staff work for the individual rather than for the system. Families, friends and staff assist people to create more meaningful relationships, link them with needed supports, remove barriers, develop safety networks, and help dreams come true - while never forgetting who is charge

## ❑ WHATEVER IT TAKES

Having an attitude that nothing is impossible. As long as it is legal and causes no harm is required. "No we can't" as an answer is replaced with "How can we make this happen?" Those who work in the system become barrier removers.



# MACROW SELF-DETERMINATION CHECKLIST

Individual: \_\_\_\_\_ Date: \_\_\_\_\_

Name of person completing the checklist: \_\_\_\_\_

Relationship to Individual: \_\_\_\_\_

Please answer each question to the best of your knowledge

0 = No

1 = Rarely

2 = Sometimes

3 = Frequently

4 = Most of the time

5 = Yes

0 - 5

Score

1. Did the individual choose their personal agent? \_\_\_\_\_
2. Was the Personal Agent (Case Manager, Support Coordinator etc.) trained to facilitate the PCP and individual budgeting process? \_\_\_\_\_
3. Did the Individual with disability agree to participate? \_\_\_\_\_
4. Did the Personal Agent & individual hold a pre-planning meeting? \_\_\_\_\_
5. Was a "targeted" individual budget amount available and used? \_\_\_\_\_
6. Were members of the circle solely invited by the individual? \_\_\_\_\_
7. Did individual choose the time, place and date of PCP meeting? \_\_\_\_\_
8. Did the process of dreaming, identifying needs/wants occur? \_\_\_\_\_
9. Were current and future supports determined using the a Planning Guide For Paid and Unpaid Companions (or similar guide?) \_\_\_\_\_
10. Were all housing options and needs/desires addressed? \_\_\_\_\_
11. Were professional and clinical needs addressed? \_\_\_\_\_

- 12. Were employment/day needs & desires addressed? \_\_\_\_\_
- 13. Were all transportation options and needs addressed? \_\_\_\_\_
- 14. Was a Personal Quality of Life Protocol completed prior to the PCP? \_\_\_\_\_
- 15. Did the Personal Agent participate in helping recruit circle members? \_\_\_\_\_
- 16. Do circle members understand their roles and responsibilities? \_\_\_\_\_
- 17. Do circle members follow through on their commitments? \_\_\_\_\_
- 18. Does the circle understand that the PCP is dynamic and the individual may request meetings, changes in the plan, circle composition or budget at any time? \_\_\_\_\_
- 19. Did the individual (or designee) approve and sign the final budget in the presence of the Personal Agent? \_\_\_\_\_
- 20. Were current (actual) revenue and expenses determined before a "target" figure was established? \_\_\_\_\_
- 20. Did the individual receive a copy of the final budget? \_\_\_\_\_
- 21. Was a Fiscal Intermediary used? \_\_\_\_\_
- 22. Was the Fiscal Intermediary selected by the individual? \_\_\_\_\_
- 23. Does the individual receive a monthly financial statement? \_\_\_\_\_
- 24. If the individual moves - does the funding follow? \_\_\_\_\_
- 25. Does the individual have access to cash or use an ATM card, credit card or personal checking/savings account? \_\_\_\_\_

**TOTAL SCORE**

## **\$\$ SELF-DETERMINATION MONEY \$\$**

**“Show Me the Money”**

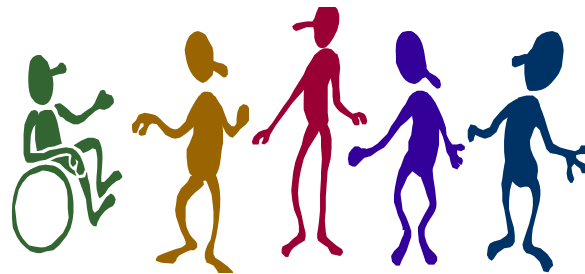
Self-Advocates who have heard about Self-Determination as well as customers involved in the Self-Determination process have heard that they have control over the money that they can use, but are often mystified by the fact that they do not have the money in hand. This exercise will help them learn where the money comes from and how they can control it.

### Materials needed:

- A large stack of Self-Determination \$1000 bills.
- Signs for all the players to wear, so that we all know their roles.

### Players:

FOCUS PERSON    Self-Determination Participant  
TAXPAYER  
SSI/SSA  
OMRDD                    State DD Agency  
BOSS or ENTERPRISE  
FISCAL INTERMEDIARY  
LANDLORD  
BANK  
SUPERMARKET/SUPERSTORE  
TRANSPORTATION       - CAR/BUS/TRAIN  
TAX COLLECTOR  
SERVICE COORDINATOR  
SUPPORT STAFF  
JOB COACH  
SUPPORT BROKER  
SERVICE COORDINATOR  
CIRCLE OF SUPPORT



The process leader chooses the focus person, the taxpayer, the state agency, the fiscal intermediary, and the tax collector.

The Focus Person chooses his or her circle of support, a Boss or business, a service coordinator, a service broker, a job coach, support staff, transportation, a supermarket/superstore, and a landlord or a bank for the mortgage.

The process leader hands out Self-Determination money to everyone including extra to the Boss. Each person gets to keep one bill, but the tax collector collects the rest and gives it to the State Agency (OMRDD) and SSI/SSA.

The Focus Person has met with his or her circle of support and has a budget of their income and expenditures.

The State agency gives the Fiscal Intermediary part of the money for the use of the Focus Person. It is the amount listed on the budget.

The Focus Person with the help of the Circle of Support decides how to spend the money. They have listed the expenses on the budget.

Now we will spend the money. The Focus Person serves as the delivery service to get the money to the right place.

The SSI/SSA \$\$ go to the Bank (personal account).

The Boss pays the Focus Person and those \$\$ go to the Bank (personal account).

Exception: OMRDD pays the Service Coordinator. (Not the Focus Person)

The Fiscal Intermediary with the Focus Person pays the Support Staff, the Support Broker and the Job Coach.

The Focus Person goes to the Bank and gets money from the personal account for the supermarket, the landlord, the mortgage, property taxes and transportation.

If more money is needed, the Focus Person applies to OMRDD.

# SELF-DETERMINATION BUDGET WORKSHEET

## SUMMARY

(Sample) 9/20/99

Name: John Demo  
Address: 10 Garden Lane, Beautiful, NY  
Phone: 914-000-000  
Social Security #: 000-00-000 TABS # 000000

Guardian: \_\_\_\_\_  
Advocate: Mrs. Demo-Mother  
DDSO: Taconic  
CIN# 000000 Date: 10/20/99

### EXPENSES

|  |             |              |
|--|-------------|--------------|
| 1. <u>Supports-Individual, program purchase, one time expenses</u>                             | <b>3100</b> | <b>37200</b> |
| 2. <u>Housing-(Rent, mortgage, taxes, utilities, furniture, supplies)</u>                      | <b>572</b>  | <b>6864</b>  |
| 3. <u>Personal-(Food, clothing, recreation, meals out, education, dues)</u>                    | <b>675</b>  | <b>8100</b>  |
| 4. <u>Transportation-(Taxi, bus, subway, auto, insurance)</u>                                  | <b>500</b>  | <b>6000</b>  |
| 5. <u>Fixed Monthly Costs- (Health &amp; life insurance, loans, spend down, prescriptions)</u> |             |              |
| 6. <u>Miscellaneous- (Medical/Dental, taxes)</u>   | <b>250</b>  | <b>3000</b>  |

### TOTAL EXPENSES

**5097      61164**

### NOTE:

The Personal Resource Account (PRA) covers both Medicaid HCBW funds and 100% State dollars. Medicaid waiver funds for eligible participants may be used to fund any needed supports and services consistent with ISP goals and the approved HCBS waiver agreement. These include but are not limited to staff, e-mods, adaptive equipment, and community participation costs. Any supplement needed for living costs (room and board), elective divisional costs not related to ISP goals and any expenses for HCBW ineligible persons must come out of 100% State funds.

### COMMENTS:

John lives with a disabled friend, sharing an apartment. He wants to control his own life. He needs support at home, at his job and to negotiate the community. He lives in a small town without access to public transportation and uses a leased car and qualified staff for transportation. He hires his own staff and pays them through a fiscal intermediary.

**INCOME****MONTHLY**   **ANNUAL**

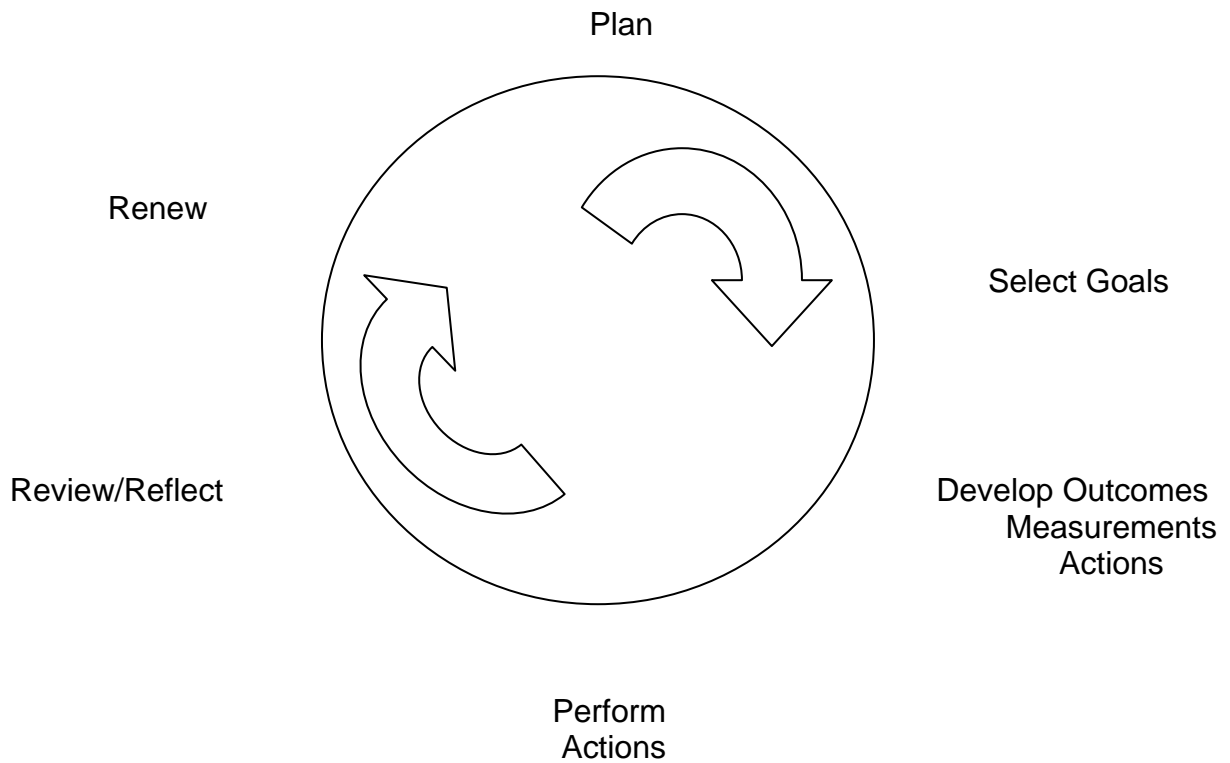
|   |                    |                     |
|---|--------------------|---------------------|
| 1. Employment                                     | 375                | 4500                |
| 2. Public Assistance                              | 0                  | 0                   |
| 3. Social security- (SSI & SSDI)                  | 662                | 7944                |
| 4. Other Benefits: VA, Black Lung, Railroad, etc. | 0                  | 0                   |
| 5. Food Stamps                                    | 10                 | 120                 |
| 6. HEAP   | 0                  | 0                   |
| 7. HUD Subsidy                                    | 0                  | 0                   |
| 8. HCBW-Consolidated Supports (CSS)*              | 3500               | 42000               |
| 9. OMRDD Supports- (100% State funds)             | 300                | 300                 |
| 10. Medicaid- (Other State Plan)                  | 250                | 3000                |
| 11. Medicare                                      | 0                  | 0                   |
| 12. Private Health Insurance                      | 0                  | 0                   |
| 13. Other Insurance: Life, Burial, etc.           | 2000               | 2000                |
| 14. Pre-paid Burial Plan                          | 0                  | 0                   |
| 15. Bank Accounts                                 | 350                | 350                 |
| 16. Other Assets                                  | 0                  | 0                   |
| 17. Other Loans and Liabilities                   | 0                  | 0                   |
| 18. Pending Litigations and Judgments             | 0                  | 0                   |
| <b><u>TOTAL INCOME</u></b>                        | <b><u>5097</u></b> | <b><u>61164</u></b> |

Note:

CSS plus 100% State funds make up  
the Personal Resource Account (PRA)

**A QUALITY ASSURANCE  
TOOL KIT  
FOR  
THE SELF-DIRECTED SUPPORTS PROGRAM**

By Pat Tangeman,  
Support Team Member



# **TOOL KIT**

## **TABLE OF CONTENTS**

1. Quality Assurance: What is it and Why do it?
2. Goal Selection Process
3. Developing the Plan:  
Outcomes, Measure and Actions
4. Action Planning Process
5. Reviewing, Reflecting and Renewing the Plan



# **QUALITY ASSURANCE WHAT IS IT? AND WHY DO IT?**

## **Quality Assurance System**

A quality assurance (QA) system is a way to measure the success of a program in meeting its intended goals and purpose. It also provides a way to find out what changes need to be made in the program to keep success occurring or to make improvements as needed.

For the Self-directed Supports statewide change, the QA system intends to find out whether the plan that each local team has developed has helped families and self advocates to chart a more self-directed path for themselves. It will help to ask whether the components of the plan really do encourage the values that were described by each local steering committee. Questions asked in the QA review process will help local teams determine what changes are needed to move plans closer to the overall goals and 3 year state guidelines.

## **Why do this?**

A systematic review of each county's program can guide the future development of the plan.

The review will promote continuous program development and improvement.

## **Why not let some experts do the evaluation and QA?**

Leaders in the field of developmental disabilities and self-determination suggest that local teams define their own QA systems especially if the overall vision of the program is the charting of self-directed paths. You developed the plan and program. You designed the program. You ought to evaluate it and make the improvements.

## **Who should develop the QA plan?**

The local group who is responsible for monitoring the plan should develop and carry out the QA plan. This group needs to have the gratification of success and the responsibility for making the necessary changes.

## GOAL SELECTION PROCESS

### Where to Start?

Start by asking the question, what important aspects of the program do you need to monitor or track? What information do you need to know to move towards a complete three year plan? How will you maintain continuous improvement of your service?

These questions could be answered by a small working group of your steering committee or could be brainstorming questions that are put to the whole group.

The intended purpose for the program – that people with disabilities and their families are defining their goals and moving towards those goals using self-directed supports would be a most likely area to monitor.

Aspects of the plan and program that you feel may need adjustments such as community outreach and linkage, selection criteria, or the accessibility of your program may be important areas to track.

As you start this process, it is recommended that you choose only a **few** areas that are **doable or achievable**. Your plans include many actions. You do not need to set up a QA tracking system for each action.

Written standards sometimes can help to define your goals. Laurie Powers, PhD., the principal investigator for the Oregon Self-determination Project, that helped to define many of the concepts necessary for self-directed supports programs and the staff of Self Directed Supports, Incorporated (SDRI), a project that is providing self-directed supports in some parts of the state have developed some standard indicators (see Appendix A). These indicators are based on their experiences with self-directed support systems. Their standards could be goal standards or outcome statements. The state guidelines could act as goal standards. Your own county standards could be goals. What is most recommended is that you select goals to be monitored that are **important** to your local team and that the tracking of progress towards these goals will give you real information that will either indicate your success or need for improvement.

## DEVELOPMENT OF THE QUALITY ASSURANCE PLAN

### Components of the Q.A. Plan:

1. **Outcomes:** Visions of the results that you want for each goal area.
2. **Measurement:** A way to know if you are making progress toward that outcome or result.
3. **Actions:** What you will do to get to your outcome.

**(Gosh, this looks like things that we have already done for the plan development)**

Right! Just choose the goal areas that you want to track!

### **Process: How to develop the components of the plan**

Once you have chosen your goal areas, a small group could develop the outcomes, measures and actions and bring a draft to the large group. For smaller counties, this activity could be done in the whole group led by the facilitator, however some preparation ahead of time with a small group would make the process go smoothly.

**Outcomes or visions** for what you want: **why do this?** Why not just use the goal statements? People who have studied creative thinking have found that if individuals or groups can learn to be more **results** oriented and spend time **visualizing** the benefit or result for themselves or others, there will be a tension between what is and where you want to go. This tension can provide both a **pull** towards the **outcome** and a **focus** for knowing when you get there. Outcomes are written in the present tense and describe future behaviors or program characteristics.

### **Some sample outcomes:**

**Goal:** **Improve the ability of people with disabilities to direct their own lives.**

**Outcome:** Families and people with disabilities use self-directed supports to realize their own individual goals.

**Goal:** **Make sure that the program is accessible to all families and self-advocates across the county.**

**Outcome:** Families and people with disabilities who need and desire supports know about the program and how to access the

program.

**Goal:**                   **Community linkages will be developed, nurtured and maintained.**

**Outcome:**           Families and people with disabilities know about services available in our community and use county self-directed supports to become a part of the community service system.

**Measurement** or how you will know when you are making progress.

When you choose a way to know when you are making progress, you usually need to **observe** some change. For something to be observable, you usually need to either count a change, see a change or see a difference. These are called **quantifiable** ways to measure progress. Quantifiable measures should also be **achievable or doable**.

People who study changes in program development or individual growth have learned that something else is needed. Sometimes change in systems just needs to be talked about or described. These ways of measuring progress are called **qualitative measures**. Ways to describe change include phone interviews about satisfaction with a program, satisfaction surveys, focus groups, and just group discussions.

To measure program results, then, it is a good idea to use both **observable** ways and **descriptive** ways. Measurement samples for the outcomes mentioned earlier follow. Appendix B contains some sample satisfaction surveys that have been used successfully by Self Determination Resources Inc.

**Samples:**

**Outcome #1: Families and people with disabilities use self-directed supports to realize their own individual goals.**

**Measurements/How will you know when you are making progress?**

1. Using the SDRI Individual Satisfaction form, 75% of people who have received services indicate that the program is doing a good job in helping individuals and families obtain the supports they want and that people with disabilities and families have achieved at least one of their goals.
2. Our service records indicate that we were able to find supports for 100% of people requesting this service.

3. Using random phone interviews, most people described the ability to meet their own individual goals.
4. A focus group of families and individuals who have used self-directed supports describe positive experiences and movement towards reaching their goals.

**Outcome #2: Families and people with disabilities who need and desire supports know about the program and can access services easily and efficiently.**

**Sample Measurements:**

1. Families and individuals with disabilities describe their positive experiences accessing the Self-Directed Supports program in focus groups.
2. Random phone calls to people who have used the Self-Directed Supports Program indicate positive experiences in accessing the program.
3. The results from the SDRI satisfaction survey indicate that 75% of people using the services did not have difficulty accessing the service.

**Outcome #3: Families and people with disabilities know about the services available in our community and use county self-directed supports to become a part of the community service system.**

**Sample Measurements:**

1. Selected satisfaction surveys indicate that families and people with disabilities use community services.
2. Focus group interactions describe how people use self-directed supports to access community services to meet their goals.

**Actions:** The action statements are what you will do to move towards the outcome. Your plan document most likely contains many of the actions steps you would use for the QA plan.

**Outcomes = results you want to create**

**Measures = how you know you are progressing**

**Action = what you will do**

# ACTION PLANNING PROCESS

## Action Planning

**Process:** A clear action plan prepares the program to move forward by designating responsibility for actions, determines when the review meeting will occur and when particular measurement activities will occur. The action plan becomes a reminder for all team members and staff and indicates a commitment to the process.

| Action   | Responsibility  | Timeline        |
|--|-----------------|-----------------|
| 1. Schedule QA review meeting for Sept. governing body meeting | Chair           | August reminder |
| 2. Send out satisfaction surveys monthly                       | SDS Coordinator | Begin in April  |
| 3. Conduct focus groups in July                                | Parent Group    | Plan in June    |

## QUALITY ASSURANCE PLAN WORK SHEET

County: \_\_\_\_\_

Date: \_\_\_\_\_

**Quality Assurance Criteria Goal:** All possible efforts will be made to ensure that the Self-Directed Supports Services are accessible to all families and self-advocates across the county.

| What will you do to make this happen?<br><b>(ACTION STEPS)</b> | What will be the benefit to families and Self advocates?<br><b>(OUTCOMES)</b> | How will you know you are making Progress?<br><b>(MEASUREMENT)</b> |
|--|---|--|
|  |   |  |

What kind of help do you need? \_\_\_\_\_

Plan Review Date: \_\_\_\_\_

Review: \_\_\_\_\_

Notes: \_\_\_\_\_

\_\_\_\_\_

## QUALITY ASSURANCE PLAN WORK SHEET

County: \_\_\_\_\_

Date: \_\_\_\_\_

**Quality Assurance Criteria Goal:** Improve the ability of people with disabilities to direct their own lives.

| What will you do to make this happen?<br><b>(ACTION STEPS)</b>  | What will be the benefit to families and Self advocates? Or results you want<br><b>(OUTCOMES)</b>  | How will you know you are making Progress?<br><b>(MEASUREMENT)</b>  |
|---|--|---|
| <ol style="list-style-type: none"> <li>1. Educate SDS staff about the role of personal support agents</li> <li>2. Provided workshops to inform community about self-directed supports and how they can help individuals and families meet their needs.</li> <li>3. The SDS coordinator assists individuals who want to hire personal support agents with names of people and helps them set up the system.</li> </ol> | <ol style="list-style-type: none"> <li>1. Families and people with disabilities use self-directed supports to realize their own individual goals.</li> </ol> | <ol style="list-style-type: none"> <li>1. Using the SDRI Individual Satisfaction form, 75% of people who have received services indicate that the program is doing a good job in helping individuals and families obtain the supports they want and they are reaching their goals.</li> <li>2. Our service reports indicate that we were able to find self-directed supports for 100% of people requesting this service.</li> <li>3. Using random home interviews, most people described positive experiences in using self-directed supports.</li> <li>4. A focus group of families and individuals who have used self-directed supports describe positive experiences.</li> </ol> |

What kind of help do you need? \_\_\_\_\_

Plan Review Date: \_\_\_\_\_

Review: \_\_\_\_\_

Notes: \_\_\_\_\_



# REVIEWING REFLECTING AND RENEWING THE PLAN

## Review, reflect and renew

**Process:** The review, reflect and renew process takes place during a decision making meeting that should end with a celebration and action planning for the next meeting. Full attendance and preparation of all members of the team is necessary for this meeting to be effective. Copies of the QA plan, the action plan and the purpose of the meeting need to be sent out to all members of the review team.

The meeting needs to be structured by goal area with a report from each person who was responsible for bringing information. Many of you have been to these kinds of review meetings. Without an exchange of information and reflection time, the meetings can be uninteresting and without a sense of completion. To encourage reflection, the facilitator can structure a discussion after each report by asking and recording: **What went well?** **What could be better?** The facilitator encourages members of the group to listen and ask questions. Next, the group leader asks the question: What are some conclusions about our progress? What changes need to be made, if any to the plan? Do additional actions need to be taken? Are the measures getting the information we need? Is this an area that we need to continue to track? Record decisions on an action plan chart or on the QA form.

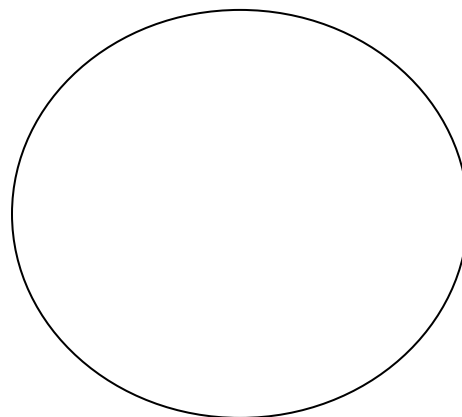
Each goal area is reviewed the same way. At the end of the review, the leader asks if there are other emerging areas that require a review. Conversations with families and individuals with disabilities may have indicated other areas that need to be monitored. A small group may develop the plan for these areas or the large group may decide.

At the end of the review, the facilitator can ask for another reflection: What went well? What might we change the team chooses a way to **celebrate** their successes and **determines** the date for the next meeting!

## Celebration

### Conversation

### Continuous Learning



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## ASSIST CUSTOMERS TO FIND AND SET UP SUPPORTS

Self-Directed Support Programs assist customers to find or create supports, to make support agreements with existing or new providers, including personal support agents, and to work with funders and customers' friends and families to set up supports that match what the customers want. The focus is on helping the customer to set up individualized supports in the community rather than 24-hour, traditional services.

This checklist shows what Self-Directed Support Programs do to assist customers to find and set up their supports. It can be used as a guide to design or evaluate the Program's activities.

| Key Activities   | Is It Happening? |    | What will we do to make it happen? |
|--|------------------|----|------------------------------------|
|  | YES              | NO |                                    |
| Assistance is given to customers who want to hire personal support.  |                  |    |                                    |
| Personal support agents can be relatives, friends, neighbors, providers or anyone else the customer chooses.   |                  |    |                                    |
| The Program offers regular help to customers and the people who assist them to find and set up their supports. |                  |    |                                    |
| Customers can find and set up their own supports, if they choose.  |                  |    |                                    |
| Program staff also are available to directly assist customers to find and arrange their supports.              |                  |    |                                    |
| Supports are set up that match only what the customer wants.   |                  |    |                                    |
| Customers can choose to use existing providers and/or to creatively set up new supports.                       |                  |    |                                    |
| The Program helps customers match their support plan with their budget.  |                  |    |                                    |
| The Program assists customers to find funding from traditional and nontraditional sources.                     |                  |    |                                    |
| The Program assists customers to make support agreements with existing or new providers.                       |                  |    |                                    |

## FISCAL INTERMEDIARY AND EMPLOYMENT SUPPORTS

Self-Directed Support Programs assist customers to hire and supervise their personal support providers and/or to set up contracts for their support with existing organizations. They also assist customers with the paperwork that has to be done to be an employer and they help customers to track their personal support budgets. The Self-Directed Support Program works with the customer and does not have a close relationship with the support providers and support agencies that the customer manages. The Program is not the employer of record for a customer's support providers.

This checklist shows what Self-Directed Support Programs do to assist customers to manage their budgets and support providers. It can be used as a guide to design or evaluate the Program's activities.

| Key Activities  | Is It Happening? |    | What will we do to make it happen? |
|---|------------------|----|------------------------------------|
|   | YES              | NO |                                    |
| Customers put in writing exactly which fiscal intermediary services they want to use from the Self-Directed Support Program.  |                  |    |                                    |
| The Program has policies that say its goal is to assist customers who want to direct their support, its primary allegiance is to the customer, not the support provider, and it is not the employer of record for the customer's support providers. |                  |    |                                    |
| The Program assists customers to be the employers of record for their support providers and/or it assists customers to set up agreements with other organizations who will be the employers of record.  |                  |    |                                    |
| Job Descriptions are written for each customer's support provider.  |                  |    |                                    |
| Support providers are chosen and supervised by customers.   |                  |    |                                    |
| No (or minimal) limits are placed on who customers can hire to be their support providers.  |                  |    |                                    |

| (Fiscal Intermediary, continued)<br>Key Activities   | Is It<br>Happening? |    | What will we do to make it happen? |
|--|---------------------|----|------------------------------------|
|  | YES                 | NO |                                    |
| Agreements are written between each customer and his or her support provider or the organization that will provide the customer's support. |                     |    |                                    |
| The Program has little direct contact with the support provider unless it is with the customer.  |                     |    |                                    |
| Benefits are available to the customer's support providers.  |                     |    |                                    |
| The Program can process employment taxes, FICA, worker's compensation, etc. for customers, and issue W-2 forms.                            |                     |    |                                    |
| Customers approve in writing the payment of all bills for their support and they are given regular budget reports.                         |                     |    |                                    |
| Checks are sent to customers to give to their support providers.   |                     |    |                                    |
| Checks can be issued within 24 hours, if needed by a customer.   |                     |    |                                    |
| The Program can get the funds for the customer's supports from the agencies or other sources that are paying for it.                       |                     |    |                                    |

## ASSIST CUSTOMERS TO MONITOR QUALITY OF THEIR SUPPORT

Self-Directed Support Programs assist customers to monitor the quality of the support they receive. Customers are assisted to monitor the quality of their supports through periodic check-ins, satisfaction surveys or postcards, and Quality Gatherings. A Quality Gathering is a group of customers who meet together to give feedback to the Program about how their supports are working and ways they could be improved.

This checklist shows what Self-Directed Support Programs do to assist customers to monitor the quality of their supports. It can be used as a guide to design or evaluate the Program's activities.

| Key Activities  | Is It Happening? |    | What will we do to make it happen? |
|---|------------------|----|------------------------------------|
|   | YES              | NO |                                    |
| Customer support plans clearly show their support goals.  |                  |    |                                    |
| Customer agreements with support providers show when they will review the quality of their support with the providers.  |                  |    |                                    |
| Customers get the assistance they want to evaluate the quality of their supports and to identify areas that need improvement.   |                  |    |                                    |
| Customers get the assistance they want to have regular meetings with their providers to review the quality of their support.  |                  |    |                                    |
| Customers regularly evaluate the quality of the assistance they get from the Self-Directed Support Program.   |                  |    |                                    |
| Customer satisfaction is regularly reviewed by the governing Board for the Program.   |                  |    |                                    |
| Individual customers are regularly invited to share their ideas for ways to improve the Program.  |                  |    |                                    |
| There are regular Quality Gatherings where customers share their experiences and ideas for improving the Program with each other, the governing Board and the Program Director. |                  |    |                                    |
| Customers are provided with the assistance they want to fire support providers who do not provide quality support and to find new providers.                                    |                  |    |                                    |

|  |  |  |
|--|--|--|
| Customers are given the name and phone number of a person in the community to contact if the Program does not improve its services within a reasonable amount of time. |  |  |
|--|--|--|

## CUSTOMER EDUCATION

Customers may want new information or skills in order to take charge of their supports. The Self-Directed Support Program helps customers to get the information and skills they want by offering individual education, workshops, and contact with mentors, or other customers who have experience and are willing to share.

This checklist shows what Self-Directed Support Programs do to assist customers to get the information and education they want to direct their supports. It can be used as a guide to design or evaluate the Program's activities.

| Key Activities  | Is It Happening? |    | What will we do to make it happen? |
|---|------------------|----|------------------------------------|
|   | YES              | NO |                                    |
| Customers are given information about what self-directed support is and the ways the Self-Directed Support Program can assist them. |                  |    |                                    |
| All customer support plans list the information, skills and experiences that customers want to choose and direct their supports.    |                  |    |                                    |
| Customers get ongoing education and assistance to manage their support budgets and to choose and direct their supports.             |                  |    |                                    |
| Workshops are conducted on topics picked by customers.  |                  |    |                                    |
| Individuals with disabilities and family members help to plan and conduct workshops.  |                  |    |                                    |
| Customers are invited to have mentors and/or to be mentors for others.  |                  |    |                                    |
| Mentors are given training and ongoing assistance.  |                  |    |                                    |
| Customers are assisted to participate in other advocacy, educational or leadership activities.                                      |                  |    |                                    |
| Customers are assisted to use the world wide web, public libraries or other information resources in the community.                 |                  |    |                                    |
| The Self-Directed Support Program has a library of resource information for customers.  |                  |    |                                    |



## CONSUMER GOVERNANCE

Self-Directed Support Programs are led by a governing group of community leaders, at least 51% of whom are individuals with disabilities and family members. The governing group is responsible for making sure that the Self-Directed Support Program does its job of helping customers to determine and direct their supports. The governing group oversees the quality of the Program's work in carrying out each of its functions, and develops goals and policies to improve the Program.

| Key Activities  | Is It Happening? |    | What will we do to make it happen? |
|---|------------------|----|------------------------------------|
|   | YES              | NO |                                    |
| The focus of the governing group is to oversee and maintain the mission of the Self-Directed Support Program.   |                  |    |                                    |
| The governing group does careful planning for the Program's future.   |                  |    |                                    |
| The governing group develops policies and reviews the performance of the Program Director of Manager.   |                  |    |                                    |
| The governing group regularly reviews how well the Program is doing its job and decides what needs to be improved.  |                  |    |                                    |
| The role and authority of the governing group is well-defined.  |                  |    |                                    |
| If the Self-Directed Support Program is part of a larger agency, there is a direct link between the governing group of the Program and the governing body of the agency (ex. a member of the governing board of the Program is a member of the governing body of the agency). |                  |    |                                    |
| More than 25% of the members of the governing group are individuals with disabilities and more than 25% are family members of individuals with disabilities.  |                  |    |                                    |
| The governing group matches the diversity of the community.   |                  |    |                                    |
| The governing group meets regularly and has a structure (ex. chairperson, president, secretary, etc.).  |                  |    |                                    |
| The governing group has a pool of people who are interested in being members.   |                  |    |                                    |

|   |  |  |
|---|--|--|
| There is an orientation program for new members.  |  |  |
| Information and written material for the governing group is presented in easy-to-understand language, pictures, etc. to make it understandable.   |  |  |
| Pre-meetings are held for members who want more time and assistance to review the agenda and the last meeting's minutes, and to figure out their viewpoints and questions for the upcoming meeting.                       |  |  |
| Assistance is provided to increase the participation of members in meetings (e.g. yes/no question-asking, taking time to review hard to understand information, notes on an easel, using straightforward language, etc.). |  |  |
| Support is given to make sure that members can attend meetings (e.g. respite, transportation, personal assistance).   |  |  |
| The governing group regularly evaluates its leadership and support for members.   |  |  |
| Members have opportunities to take part in activities to increase their knowledge and leadership skills.  |  |  |

## COMMUNITY BUILDING

The Self-Directed Support Program conducts forums and workshops in the community to educate people about self-directed support and to increase the number of self-directed support providers. Staff also work with other organizations to increase the support options available in the community.

This checklist shows what Self-Directed Support Programs do to build community supports. It can be used as a guide to design or evaluate a Program's activities.

| Key Activities  | Is It<br>Happening? |    | What will we do to make it happen? |
|---|---------------------|----|------------------------------------|
|   | YES                 | NO |                                    |
| Training is given to people who want to be personal support agents.   |                     |    |                                    |
| A registry of personal support agents is kept for customers.  |                     |    |                                    |
| The Program does regular workshops about self-directed support for agencies, organizations and community members.   |                     |    |                                    |
| The Program does projects with other organizations and agencies to increase the self-directed support options in the community.                                     |                     |    |                                    |
| The Program shares information and resources with other organizations that can assist customers.  |                     |    |                                    |
| The Program builds relationships with foundations and organizations that give grants in order to increase their understanding and funding of self-directed support. |                     |    |                                    |

## CUSTOMER SATISFACTION SURVEY

Our records show that you recently met with a support broker at Self-Determination Resources, Inc. (SDRI). The Board of Directors at SDRI wants to know how satisfied you are. Please complete and mail back this postcard. Your individual answers will not be shared with the staff. We encourage you to tell SDRI staff when they are doing a good job or that you want better services.

**1. My broker listened to my needs and understands me.**

Great job                  Good job                  Needs work                  Help!

**2. I got the information and help I need to make decisions.**

Too much                  Right amount                  Not enough                  Confusing

**3. The plan we developed is what I want.**

Exactly                  Close                  Needs work                  Help!

**4. I would recommend SDRI to a friend.**

Yes                          No

Comments:

---

### OPTIONAL

If you would like to talk with someone about your experiences at SDRI, please

Write your name and phone number below.

Name: \_\_\_\_\_

Phone: \_\_\_\_\_

## QUALITY QUESTIONS FOR INDIVIDUAL AND FAMILY CUSTOMERS OF SELF-DIRECTED SUPPORT

It is important that you have the support you need to be safe and to live the way you choose. **You are in charge of deciding whether you are receiving the support that you need.** Please answer the following questions that ask about the quality of your life and support. Feel free to write any comments or ideas. If you need assistance to answer these questions, please call \_\_\_\_\_.

### YOUR GOALS

Listed below are the goals you had the last time you planned your supports. For each goal, circle whether you achieved it, you're making progress, you're stuck, or it's not important any more.

Goal: \_\_\_\_\_  
\_\_\_\_\_

|                        |                 |           |               |
|------------------------|-----------------|-----------|---------------|
| Achieved it<br>Anymore | Making Progress | I'm Stuck | Not Important |
|------------------------|-----------------|-----------|---------------|

Goal: \_\_\_\_\_  
\_\_\_\_\_

|                        |                 |           |               |
|------------------------|-----------------|-----------|---------------|
| Achieved it<br>Anymore | Making Progress | I'm Stuck | Not Important |
|------------------------|-----------------|-----------|---------------|

Goal: \_\_\_\_\_  
\_\_\_\_\_

|                        |                 |           |               |
|------------------------|-----------------|-----------|---------------|
| Achieved it<br>Anymore | Making Progress | I'm Stuck | Not Important |
|------------------------|-----------------|-----------|---------------|

## YOUR SATISFACTION WITH LIFE AND THE SUPPORTS OR SERVICES YOU GET

| Parts of life                                   | Are you satisfied? |    | Are you getting the support or services you need? |    | Put a check (✓) if you want To change or improve something. |
|---|--------------------|----|---|----|---|
|   | (Circle Yes or No) |    | (Circle Yes or No)                                |    |   |
| Where you live                                  | Yes                | No | Yes   | No |   |
| Your job or day activity                        | Yes                | No | Yes   | No |   |
| Your medical care                               | Yes                | No | Yes   | No |   |
| Your opportunities to have fun and meet friends | Yes                | No | Yes   | No |   |
| Transportation                                  | Yes                | No | Yes   | No |   |
| Other area of life<br>(write it in)             | Yes                | No | Yes   | No |   |

Do you have a personal agent (someone who works for you to arrange the support you need)? Yes      No

If yes, are you getting the help you want from your agent? Yes      No

Are there supports or services that you need and you don't get? Yes      No

What additional supports do you need?

Are there times when you don't feel safe? Yes      No

### SUM IT UP

Look over your answers. Do you want to change anything to safe or happy? Yes      No

What would you most like to change or improve?

---

We want to help. Would you like some assistance to change or improve anything? Yes      No

THANKS FOR DOING THIS QUESTIONNAIRE. PLEASE MAIL IT BACK IN THE ENCLOSED ENVELOPE. IF YOU HAVE ANY QUESTIONS, PLEASE CALL \_\_\_\_\_

## HOW'S OUR BOARD DOING?

### Our Mission and Goals

1. The overall mission or purpose of our Board is clear to members.

\_\_\_\_\_ yes

\_\_\_\_\_ no

2. We are making progress in achieving our goals.

\_\_\_\_\_ yes

\_\_\_\_\_ no

3. Our meetings are productive.

\_\_\_\_\_ Always

\_\_\_\_\_ Sometimes

\_\_\_\_\_ Rarely

4. Our Board is strong.

\_\_\_\_\_ yes

\_\_\_\_\_ on our way

\_\_\_\_\_ no

**What could be done to help clarify or move forward the mission and goals of our Board, to make our Board stronger?**

## **Program Management**

5. We understand what our Program does for customers.

\_\_\_\_\_ yes  
\_\_\_\_\_ no

6. Our program policies are adequate.

\_\_\_\_\_ yes  
\_\_\_\_\_ no

7. We are able to adequately oversee and guide the work of our Brokerage Manager.

\_\_\_\_\_ yes  
\_\_\_\_\_ no

Suggestions for ways to improve our Board's management of the Program.

## **On a Personal Level**

8. I feel good about my contribution to the Board.

\_\_\_\_\_ yes  
\_\_\_\_\_ no

9. I feel like the effort I put into the Board is worth it.

\_\_\_\_\_ yes  
\_\_\_\_\_ no

10. I have the information I need to fulfill my Board role.

\_\_\_\_\_ yes  
\_\_\_\_\_ no

11. I have the skills and support that I need to fulfill my Board role.

\_\_\_\_\_ yes  
\_\_\_\_\_ no

**What do you need to increase your effectiveness/satisfaction on the Board?**



**THERE'S  
NO PLACE  
LIKE HOME**

*Some things to think about when deciding where to live.*

Developed by Deb Griffin Kney  
Advocates in Action/PAL  
Box 41528  
Providence, RI 02940-1528  
Voice: (401) 785-2028/2100 ♦ (508) 252-5601  
Fax: 401-785-2186

## ***DID YOU KNOW***

◆ Rhode Islanders who have a developmental disability live in lots of different places around the state.

some live with their family and some live in group homes. Others live in their own apartment. Some also own their own home.

◆ You don't have to live alone. You could have a roommate.

If you move into a place with a roommate who also needs support. You can "share" a staff person to, help cover the hours that each of you might need them to be there.

◆ If you don't know how to do some things it may take to live in your own home (like pay bills, clean or cook), you can get help to learn

◆ You don't need to know how to do everything before you move into your own home.

◆ You could live in something called a subsidized apartment. This means the Government will help you pay your rent.

You have to apply for a subsidized apartment by filling out some paperwork. Many service providers can help you do this.

## **QUESTIONS TO ASK YOURSELF and YOUR ANSWERS**

✓ Where do you want to live? Country or city? On the bus line? In a house or apartment? Who do you want to live with? Write a few of your ideas:

---

---

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---

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✓ Are you living in a decent and safe place? Is it clean? Is it comfortable?

**YES -or- NO**

If you answered the last question “NO”, explain why you think your home is not clean or safe. What do you want to see different? \_\_\_\_\_

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- ✓ If you're thinking about moving, do you have enough money to do it? Rent or a mortgage, food and utilities are some of the things you will have to pay for. Can you think of some other things you will have to pay for? Write them here:

---

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---

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- ✓ Some people decide to have roommates to help share expenses or to keep them company. Have you thought about having someone as a roommate? What qualities do you want in a roommate? Here is a list of some. Check off the ones that are important to you and add others:

My roommate ...

- ... needs to be the same sex as me
- ... needs to have some support staff hours so we can share
- ... needs to be able to pay: \$\_\_\_\_\_ for rent and utilities
- ... needs to be able to do their share of the housework
- ... needs to be someone close in age to me
- ... needs to give me “my space” – and not expect to do everything together
- ... needs to \_\_\_\_\_

- ✓ Where do you want to live? Near your job? Near family? Near friends? In the country? In the city? On the bus line? In a house? In an apartment? List your answers:

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## **DECISIONS!**

Moving is a BIG decision! If you are thinking about getting your own place, be ready to tell friends and family why you want to do it. Is it ***the most important thing*** that you want? Why? Write your answer:

---

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Now that you've found out about housing, and asked yourself some important questions, you may have decided to move, or to ask for more support where you live right now. Whatever you decide that you want and need, **GO FOR IT!!** Here is a list of some possibilities. Check off the ones that are most important to you. Don't be afraid to dream! Things don't need to happen overnight!

- Learn how to do different things I'll need to live on my own. Here is a list of some things to learn. Circle your top three or add others:

**COOKING**

**CLEANING**

**SHOPPING**

**BANKING**

**TAKING A BUS**

**USING THE PHONE**

**TAKING MEDICINE**

**YARD MAINTENANCE** \_\_\_\_\_

- Move to my own place to live. Here are some things to do first. Circle all that you need and write others. I need to:

- ◆ Find an agency to help me
- ◆ Learn the right questions to ask landlords
- ◆ Decide how much I can afford
- ◆ Find a roommate
- ◆ Look for a place to live
- ◆ Get furniture, towels and dishes
- ◆ Apply for subsidized housing
- ◆ Move my belongings
- ◆ Other:

- My parents/family that I live with are getting old and it is hard for them to help me like they used to at home. I need someone to come to my home and help me so I can continue living with them. The things I need help with at home so I can keep living there are:

---



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---



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- I want to make some changes to my home so I can get around easier. Some changes people make are: a ramp, hand bars in the bathroom, and wider doorways. The changes I need to make are:

| <b>CHANGE TO MAKE</b>          | <b>REASON I NEED TO MAKE IT</b>   |
|--------------------------------|---|
| For example: I need a new ramp | My father used to carry me into the house because I couldn't get my wheelchair up the stairs. He can't do it any more. I need to get in my house! |
|                                |   |
|                                |   |
|                                |   |

- I need extra emergency help to live in my home. Right now I call this person/number if there is an emergency:

\_\_\_\_\_

I need someone else to call.

- I need to learn to use 9-1-1 for emergencies when I can't reach family, friends, or my staff support.

- I need a person to help me with personal care in my home. Some of the things I need this person to help me do are:

HELP ME TO TAKE A  
SHOWER OR BATH

HELP ME  
IN THE BATHROOM

HELP ME WITH THESE  
MEDICAL ISSUES:

OTHER THINGS:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Other things I think I need or want that will help me to live in the place that I want, with the people that I want are: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Are you making some decisions about housing? You can call or write the Division of Developmental Disabilities, or any of the other Resource Networks listed at the back of this book for help. They can give you more information. They can also help you walk through this booklet to make some decisions if you aren't sure. Either way, call or write today.**

## THINKING ABOUT MOVING

Objective: Get people brainstorming ways to overcome some “obstacles” to moving/living on their own (also helps promote teamwork!)

What to do:

- ❖ Number 8 ½ x 11” pieces of paper 1-50
- ❖ Tape/place paper on floor – connecting pieces in a “trail” to make a large “game board”
- ❖ Divide class into 2 teams – one person from each team is the game marker for their team
- ❖ Decide who goes first and give that team an “obstacle card”
- ❖ Team will work together to brainstorm a solution. Then they share the solution and spin to move ahead. The game marker moves ahead that many spaces.
- ❖ Each team gets one turn – brainstorms until they come up with a solution – if they “give up” they don’t move. (Don’t EVER give up!)

Nope, there isn’t much “strategy” to this game – just a roll of the dice! *But ...* the life size game board and interactive players as game pieces – plus each team brainstorming solutions makes it FUN!

Developed by Deb Kney, PAL  
Box 8885, Cranston, RI 02920

Phone: 401-785-2100/508-252-5601, fax: 401-785-2186, email: [debg@ids.net](mailto:debg@ids.net)

These are some Obstacle Cards – You can make others. Ask the class members what types of obstacles they have faced or think about facing in regards to moving.

**YOU DON'T KNOW HOW TO  
READ THE APARTMENT ADS  
IN THE NEWSPAPER**

**YOU ONLY HAVE A BEDROOM  
SET. YOU DON'T HAVE ANY  
OTHER FURNITURE FOR YOUR  
NEW HOME**

**YOU DON'T HAVE ANY  
KITCHEN UTENSILS.**

**DON'T KNOW HOW TO  
HANDLE MONEY**

**STAFF AT YOUR WORKSHOP  
TELL YOUR PARENTS YOU  
AREN'T "READY" TO MOVE  
BECAUSE YOU CAN'T COOK**

**YOU WANT TO MOVE, BUT YOU ARE  
AFRAID TO LIVE ALONE**

**YOU DON'T THINK YOU CAN  
AFFORD AN APARTMENT ON  
YOUR OWN**

**YOUR PARENTS TELL YOU  
THEY ARE AFRAID YOU MIGHT  
GET HURT IF YOU MOVE INTO  
YOUR OWN APARTMENT**

**YOU COULDN'T GET IN THE  
DOOR OF THE APARTMENT  
YOU WERE GOING TO LOOK  
AT BECAUSE THERE WASN'T  
A RAMP.**

**YOU DON'T KNOW HOW TO DO  
LAUNDRY**



# SELF-ADVOCACY AND SELF-DETERMINATION ROLE PLAYS



## BECOMING A SELF-ADVOCATE

Location: Self-Advocacy convention

Situation: You are participating in a workshop and they want to know what you think makes a good self-advocate.

Role Play: What skills can you learn about to be a better self-advocate?

Do you know your rights?

How can you learn more about your rights?



## BEING A SELF-ADVOCATE

Location:Where you live

Situation:Someone keeps taking your mail.

Role Play:How can you find out who is taking your mail?



Talk to the person who is taking your mail.

Let them know mail is a personal thing and they do not have a right to take yours or open it up without your permission.

## ADVOCATING

Location:At your lawmaker's office

Situation:You are talking to your lawmaker about how funding cuts will affect your life.

Role Play:Explain how the services you receive help you.



Explain what would happen if some of your services were taken away. Tell them about things you do in your community.

## EXPRESSING YOURSELF

Location: Work

Situation: Your boss is having a meeting. He is starting up a baseball team for fun after work. He is asking if anyone is interested in playing.

Role Play: Let him know that you would like to play.



If you can not play, can you help in other ways?

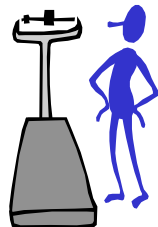
How often are they going to meet?

## KNOWING ABOUT YOURSELF

Location: The doctors office, your mom is with you.

Situation: You are not feeling well, and the nurse is asking you questions.

Role Play: When the nurse asks, you tell her what is bothering you.



Give the nurse your name and age.

Can you tell her your address and phone number?

## BEING RESPONSIBLE

Location: A department store

Situation: It's payday, and you see a new soccer ball that you would love to have.

Role Play: If you buy the soccer ball will you have enough money to pay all your bills.



Do you have a ball at home that is still good?

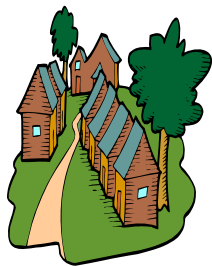
Do you need to save some money each payday to buy the ball?

## FREEDOM TO CHOOSE

Location: A meeting with your case manager

Situation: You are telling everyone where you want to live.

Role Play: Talk about your self-determination!



Let them know where YOU want to live, not where they think you should live.

Do you want to live alone, or with a friend of your choosing?

Would you like to have a dog?

# YOUR SUPPORTS

Location:Your home

Situation:You are having a meeting with your case manager. You are not happy with the supports you are getting.

Role Play:What do you need that you are not getting?



Does the staff meet your needs?  
Do you need less help?  
Do you need help with cooking?  
Who makes the decisions?

# AUTHORITY

Location:Your home

Situation:You are on the phone with your support person.(family, case manager)

Role Play:You have a bank account with money in it that will pay for your needs.



You have a new worker and you need help making sure she gets paid.

What else might you need help with?

# YOUR PERSONAL SELF- DETERMINATION ROLE PLAY

Location: Any where!

Situation: You tell us what Self-determination means to you.

Role Play: Do you like extra sauce on your pizza?



Do you want to learn to dance?

Would you like to go swimming?

Would you like to take a rest?

What is important to you right now?