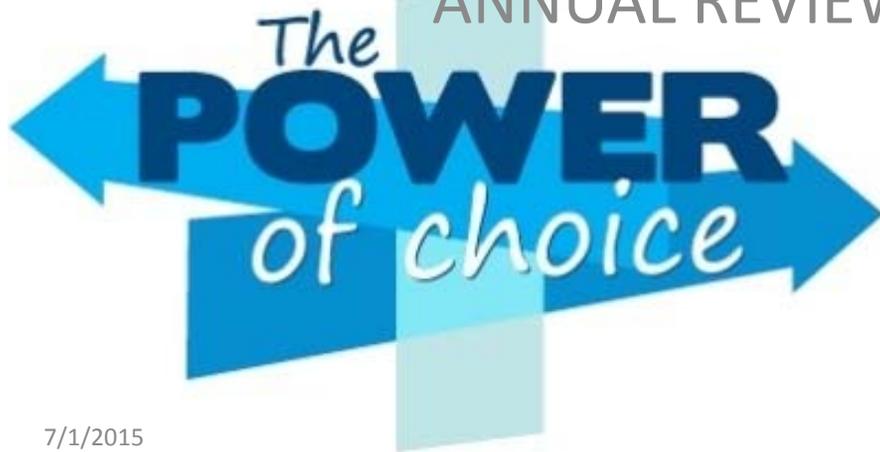


An Overview of Self-Determination and DDS Service Models

ANNUAL REVIEW FOR ALL DDS STAFF

2015



INTRODUCTION

- Self-Direction is a way of providing supports to individuals that promotes personal choice and control over decision making. This includes allowing individuals and/or families to decide **who** provides those supports and **how** and **when** they are delivered.
- Self-Direction is based on the idea that individuals and/or families are in the best position to know what they want and need.



.... Continued

- DDS is committed to investing in models of service delivery that allow people receiving services to have choices about how their services are provided.
- Over the past several years DDS has developed service delivery options that offer people more decision making and control regarding what services they need (and don't need) and how the services can be provided to best help them.



.... Continued

- A new law* that further supports and strengthens these values and commitments was signed on August 6, 2014. It is commonly referred to as the Real Lives Law.
- This review will offer an overview of the service delivery options and explain the concept of self-determination. It will be provided to all DDS staff annually as required by this law.

*Chapter 255 of the Acts of 2014

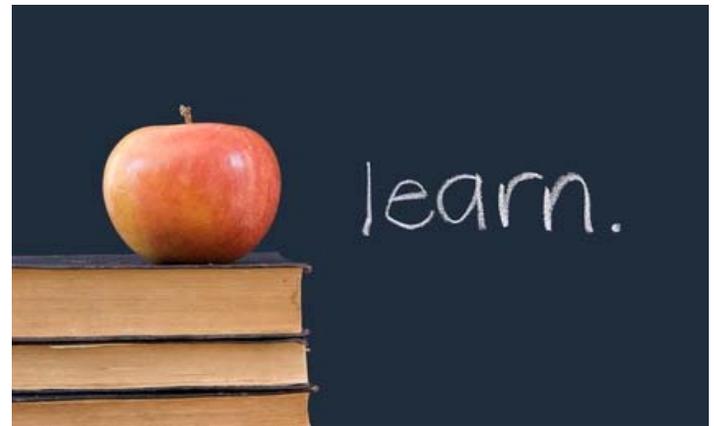
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- The Centers for Medicare and Medicaid Services (CMS) is the federal agency that provides funding for many DDS services. In 2014, CMS published a Final Rule* for Home and Community Based Waiver (HCBW) programs. Below are **just a few** of the requirements specified in the Final Rule that further promote self-direction.
 - Ensure the individual receives services in the community to the same degree of access as individuals not receiving Medicaid home and community-based services.
 - Person-centered service plans document the options based on the individual's needs, preferences and whether an individual chooses to self-direct services and for residential settings, the individual's resources.
 - Optimizes individual initiative, autonomy, and independence in making life choices.
 - Facilitates individual choice regarding services and supports, and who provides them.

*Final Rule CMS 2249-F/2296-F was published in the Federal Registry on January 16, 2014.

What Will I Learn From This Review?

- ❖ The Traditional Model – what it is and who can receive these services.
- ❖ Descriptions of other models and the impact of self advocacy and family advocacy organizations on the new models developed.
- ❖ The concept of self-determination.



What Will I Learn From This Review? -Continued

- ❖ The Agency With Choice Model – what is it and who can choose this model.
- ❖ The Participant Directed Model – what is it and who can participate in this option.
- ❖ The difference between self-determination and self-direction, and the three DDS models of service delivery.
- ❖ Initiatives and recent developments related to self-determination and self-direction.



What Is The Traditional Model of Service Delivery?

The Traditional Model of community supports began with the closing of large state institutions and has been available to individuals/families for almost a half a century. It is the most commonly used model in Massachusetts.

In this model, the provider agency (pre-qualified and licensed agencies) contracts directly with DDS to deliver a specific range of supports (e.g. shared living, group homes, employment and day programs) to the individual. The agency has full authority and responsibility for hiring, training, supervising and paying employees.



DEPARTMENT OF DEVELOPMENTAL SERVICES



What Is The Traditional Model Of Service Delivery? - Continued

The individuals, their families and service teams develop Individual Service Plans (ISP) and provide input on other day to day decisions (e.g. activities in and out of home, meal choices and the time of meals, bedtime, furnishings etc.).

The provider agency has the responsibility for managing all aspects of the budget so that the services in the contract and ISP are provided according to applicable federal and state laws, DDS and other state regulations, as well as other DDS requirements.

Who Can Receive Traditional Services?

To receive traditional services a person must:

- 1) be eligible for DDS supports
- 2) have an assessed need for the services to be provided
- 3) if applicable, be prioritized for DDS services



Example Of A Traditional Model

Jane is a 68 year old woman who lived independently in her own apartment with a few hours a week of individual supports. Staff would stop by and help her with shopping, banking and other assistance as needed to help her live independently.

Four years ago, Jane was diagnosed with diabetes and high cholesterol. She had a series of strokes which left her unable to walk and with a limited ability to speak. She was no longer able to live independently.

Example Traditional Model - Continued

Jane moved into a 24 hour staffed apartment with three roommates. She was very unhappy with this dramatic change in her life. Jane remained unhappy and was requesting to move yet again.

Jane's Service Coordinator was concerned. She met with Jane and asked her what she would need in order to be happy in a new home setting. Jane was very clear.

Example Traditional Model - Continued

She wanted to have a peer group that she could communicate with, to eat later than the set supper time, to have her own bedroom, painted in shades of blue and green, and to attend self advocacy groups on her own.

Together, Jane and her service coordinator made referrals to provider agencies that could not only support her medically, but also agreed to Jane's very specific requirements. Jane met with two different providers and selected the one that could support her in the areas that mattered to her.

Example Traditional Model - Continued

She moved into this home and has lived there for 14 months with no plans to move. Jane is happy with her choice and is enjoying a rich and rewarding life.



Why Were Other Service Models Developed?

The concept of **Self-Determination** arose from local, state and national self advocacy and family advocacy movements and have led to human services system changes across the country. Many individuals and families sought alternatives to the traditional service delivery system. They wanted to take more control of their lives to make service decisions, choose their provider, and hire their staff.



Why Were Other Service Models Developed? - Continued

The self-determination movement resulted in the development of new service models. In Massachusetts, these new models are generally referred to as “self-direction.”



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Why Were Other Service Models Developed? - Continued

DDS now offers two self-directing models in addition to the Traditional Model. The range of these three DDS service delivery models offers people the opportunity to choose the option that best fits the degree to which they wish to exercise self-determination in their lives.



Why Were Other Service Models Developed?

- Massachusetts, and most other states, began incorporating self-direction into the service delivery system in the 1990s. Experience has demonstrated that offering a range of models is cost effective and most importantly, results in outcomes for many individuals that are positive and fulfilling.

Message from a Self Advocate

This is John Anton, a Self Advocate. John has dedicated his life toward the improvement of services for all people with special needs. He works as a Legislative Aide for a MA State Representative and is a member of the Self-Determination Advisory Board. He has received several state and national awards. John self-directs his DDS funded support.



John says...

“Self-Determination is our Right!

We need to have control over our choices-not to be told what we can and cannot do!

- *If we are not at the table in the plans about our lives, we may end up with a menu of services we do not want.*
- *We want what everyone else wants: Meaningful relationships, being valued, being included, meaningful work!*
We can have these things even if we need support.”



“A Place to Call Home”

Comments from Family Members About Self-Direction

The following are quotes from families regarding self-direction.

- *“The flexibility of participant direction makes it possible to quickly make things happen.”*
- *“You don’t have to wait for someone at an agency to give you prior approval to address a given need.”*
- *“My son is in control, he chooses what he wants to do...”*



Comments from Family Members About Self Direction - Continued

- *“My daughter needed the flexibility available in self-directed supports. Without it, her quality of life wouldn’t be possible.”*
- *“Self-Direction gives my son more confidence and esteem because he has a real voice.” “ My son sees his siblings doing all kinds of things. He wants to have the same opportunities and choices that they have. I just want him to be happy.”*



What Is Self-Determination?

Self-Determination is the concept of having control in one's life to make choices based on preferences, beliefs and abilities to influence one's future.



Principles of Self-Determination*

- **Freedom** to decide how one wants to live his or her life
- **Authority** over a targeted amount of dollars
- **Support** to organize resources in ways that are life enhancing and meaningful to the individual
- **Responsibility** for wise use of public dollars and the recognition of the contributions individuals across disability and aging can make to their communities
- **Confirmation** of the important roles individuals must play in the newly designed system

*From the website www:centerforself-determination.com



How Can Individuals Achieve Self-Determination?

Individuals determine the course of their lives by designing and directing their own services. This process is called **self-direction**. There are two DDS models of service delivery to direct one's services:

- Agency With Choice (AWC)
- Participant Directed Program (PDP)



What Is Agency With Choice?



The Agency With Choice (AWC) model allows individuals and families to purchase services and to choose and supervise their staff and other supports without having to be responsible for regulatory, accounting, legal and technical duties associated with being an employer and purchaser of goods and services. The provider agency is responsible for hiring staff and purchasing goods and services.

What Is Agency With Choice? - Continued

When hiring staff to provide services, the individual/family may choose their own employee candidates provided those candidates meet agency requirements, or they may choose from available staff people who are employed by the agency.

The individual (or family) also makes other decisions about how to use their DDS funded allocation.



What Is Agency With Choice? - Continued

In this model

- **The provider agency** is responsible for hiring the staff, for all duties of an employer, and for appropriate purchasing of all goods and services. The provider agency is responsible for managing all aspects of the budget so that the services in the contract and ISP are provided according to applicable federal and state laws, DDS and other state agency regulations, and other DDS requirements.



What Is Agency With Choice? - Continued

- **The individual/family** selects the employees he/she recommends or employees made available through the agency, sets work hours and terms of employment, provides daily supervision and management of employees, and determines when that staff person is no longer needed.
- **The provider agency and individual/family** share in training and evaluating employees.



Who Can Choose the AWC Model?

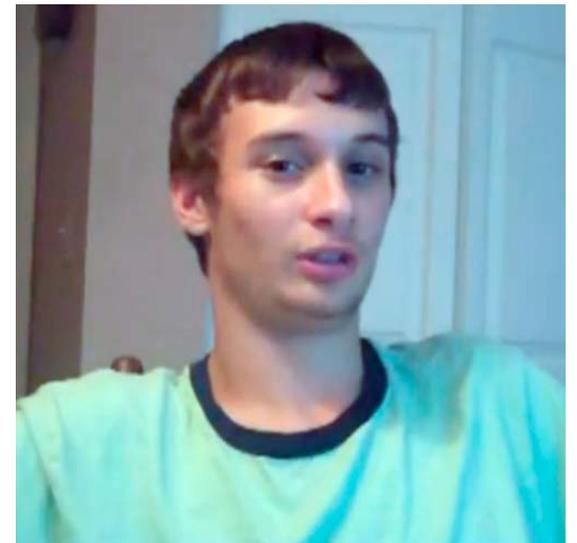
To participate in AWC supports, a person must:

- 1) be eligible for DDS supports
- 2) have an assessed need for the services to be provided
- 3) if applicable, be prioritized for DDS services
- 4) be willing and able to work cooperatively with the provider agency
- 5) be responsible for the day-to-day management and supervision of the employees



Example of Agency with Choice

Sean is a young man who turned 22 in September. He has a diagnosis of intellectual disability and autism. Sean has great difficulty being in a group setting because of his reaction to loud noise and his adverse reaction to crowds. He had a very individualized educational day program provided by his school system, primarily consisting of 1:1 activities in an isolated setting.



Example Of Agency With Choice - Continued

Sean's parent's vision for him included developing friendships and learning skills necessary to become employed.

They decided to pursue the Agency with Choice model for services because they wanted to self-direct services but with the assistance from the agency to be responsible for the employee related functions.



Example Of Agency With Choice - Continued

With the help of his AWC provider, they created a community based program where Sean is involved in community volunteer activities and his interactions with others can be limited. They also created an internship with Papa Gino's. The company allows Sean to come to their restaurant before it opens to learn skills related to food preparation and facility cleaning. Sean spends two hours, three days a week at Papa Gino's with his support staff. He leaves just before the restaurant opens.



Example Of Agency With Choice - Continued

The goal is to introduce Sean gradually to patrons when few customers are there, and then increase his time with others at the restaurant as tolerated. The family has found that the AWC model allows them to have as much control over Sean's supports as they feel they can handle at this time. The relationship between Sean and the AWC agency has been beneficial to both he and his parents. Sean will have opportunities to grow over the coming years through the unique supports created for him in this model.



What Is The Participant Directed Program Model?

The Participant Directed Program (PDP) option offers the individual/family the most flexibility to arrange and customize supports based on the individual's needs and preferences. The individual can hire their own support staff, design their schedule, and make other decisions about how to use their DDS funded allocation.



Participant Directed Program - Continued

In the Participant Directed model:

- **The person and/or family** self-directing makes their own decisions, determines how their DDS funding is spent for services, supports and goods (within DDS guidelines), and takes responsibility for the decision he or she makes.



Participant Directed Program - Continued

- **A fiscal intermediary (FI)** serves as the agent for individuals and families and is responsible for all payments. The FI pays support staff, and other goods and services in accordance with the participant's budget. The FI provides financial monitoring and reporting and ensures compliance with all applicable federal and state laws, DDS and other state agency regulations, and with other DDS requirements.



Participant Directed Program - Continued

- **A Support Broker**, typically a DDS Service Coordinator, helps the person define his or her needs and dreams through a person centered planning process that leads to an Individual Service Plan. The Support Broker helps the individual create and manage a budget within the allocated resources, and develop a network of services/supports.

The Support Broker also acts on behalf of the individual to arrange for needed services, to provide information on resources and to support the individual in evaluating the effectiveness of supports.



What Are Some Other Key Components of the Participant Directed Model?

The **Individual Budget** is a mechanism that enables a participant to direct and manage the delivery of services he or she is authorized to use.

By utilizing the budget an individual has:

- control of a specific amount of funds and
- the responsibility and freedom to purchase supports, services and goods from a variety of sources.



What Are Some Other Key Components Of The PDP Model? - Continued

DDS completes the process to **qualify staff** hired by the individual. All staff employed in this model must:

- be at least 18 years old
- have a CORI (Criminal Offender Record Information)
- have a high school diploma or GED (General Education Development) Certificate

A driver's license is frequently required.

Other education, credentials, and/or experience may be required for some services (e.g. nursing and other therapeutic services).



Who Can Enroll in the Participant Directed Program?

To enroll in the Participant Directed Program (PDP), a person must:

- 1) be eligible for DDS supports
- 2) have an assessed need for the services to be provided
- 3) if applicable, be prioritized for DDS services
- 4) receive a DDS allocation
- 5) be willing and able to work cooperatively with a Support Broker
- 6) be responsible, working closely with a Support Broker as needed, to manage their services and budget

Individuals meeting the above criteria in adult services, children in the Department of Elementary and Secondary Education (DESE) program, and adults in the Autism Services Division may choose the Participant Directed Program as their method of service delivery. All participants in the Children's Autism Waiver program direct their services.

Example of Participant Directed Program

Lisa says, “ I feel more like an adult!”

Lisa is a 34 year old woman with a million dollar smile that lights up a room. She was adopted by her foster mother who later became her legal guardian. When her mother bought a building with a separate apartment, Lisa had an opportunity to move there and work on becoming more independent. Lisa jumped at the chance.



She decided to self-direct her own services through the Participant Directed Program. She purchased Individualized Home supports by hiring a worker to visit each week and help her stay on track with her goals.

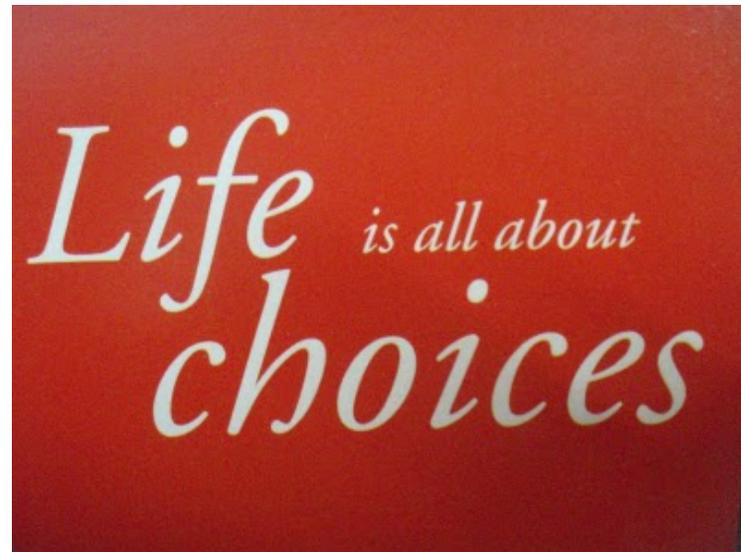
Example Of PDP - Continued

The first worker didn't provide her with the supports she needed so she interviewed and hired a different person. With the support of her current worker, she has grown by leaps and bounds. For example, after taking a cooking class Lisa decided she wanted to cook more independently at home. Previously she never had any real interest in cooking and relied on others to prepare meals for her. Lisa set her mind to it and now cooks meals at home on a regular basis. A few years ago she joined a Zumba class. That experience brought out the natural born leader in Lisa and she is very helpful with others that need more assistance. She is always willing to lend a hand to teach someone something.



Example of PDP Continued

Being able to make her own choices through self-directed services has strengthened Lisa's confidence and willingness to try new things. Lisa feels her biggest accomplishment is her comfort in negotiating with her mother. Lisa used to doubt herself, now she can talk with her mother about decisions she is making.



Review of Terms Used

- **Self-Determination** is the concept of having control in one's life to make choices based on preferences, beliefs and abilities to influence one's future.
- **Self-Direction** is a process through which individuals determine the course of their lives by designing and directing their own services. In Massachusetts the two service delivery options that offer different levels of self-direction are the Agency With Choice and Participant Directed Program models.



Review Of Terms - Continued

- In **Agency With Choice** the individual negotiates with the agency (with assistance) in the design of his/her services and directs their staff without the administrative and paperwork responsibilities associated with being an employer and managing a budget.



Review Of Terms - Continued

- **Participant Directed Program** offers the individual the most control, authority and responsibility over his/her services and budget. It includes support for the individual to design, plan, monitor and evaluate services and a system that manages paperwork, accounting and compliance.



Reporting Financial Abuse

- The Real Lives Law requires any member of a participant's chosen planning team, any member of the SDAB, any mandated reporter of the DPPC...and any other person involved in the preparation or implementation of the self-determination plan who **suspects financial abuse, including, but not limited, to mismanagement, misappropriation or waste of a participant's self-determination funds or individual budget** shall immediately report such suspicious actions or inactions to the DPPC.
- This requirement is in addition to the pre-existing mandate to report to the DPPC suspected physical and/or emotional abuse of a person with a disability.

Reporting Abuse

Call the DPPC 24-Hour Hotline at

1-800-426-9009

1-888-822-0350 TTY

In Case of an Emergency

Call Local Police or 911

followed by a call to the DPPC

Initiatives and Recent Developments

- **DDS is Expanding Self-Determination and the Use of Self-Directed Supports**

In fiscal year 2015, DDS added four regional positions to focus entirely on expanding the participation in self-direction.

These four regional managers will work together to provide consistent leadership, coordination,

management and oversight in the effort to develop and expand the use of self-direction in their regions. They also play a key role in working with Area and provider agency staff to identify and encourage individuals who want to explore the self-direction options available.



Initiatives and Recent Developments- Continued

- **Real Lives Law**

This law has many provisions and requirements, including the training for all DDS staff. One provision is the establishment of a 22 person Advisory Board to advise DDS on matters relative to self-determination. The board is comprised of the following members :

- individuals and families who are currently self-directing
- advocacy and provider agency representatives
- representatives from DDS, Disabled Persons Protection Commission (DPPC), the State Auditor, Attorney General and Inspector General

The DDS Self-Determination Advisory Board (SDAB) began meetings in January of 2015. See next slide for where to access more information on the law and the work of the SDAB.

For More Information On Self-Determination in DDS

Go to mass.gov/ehhs/dds. Look on the far left column and click on Self-Determination.

On this site you will find documents related to DDS work on self-determination from the past several years as well as links to the Real Lives Law, the SDAB membership list, the Work Plan related to the law, links to provider agency information and much more. You can also provide feedback to DDS via this website and through the feedback form for this review.

Thank you for your time and attention!