



SELF DETERMINATION NEWSLETTER

State Of Connecticut

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Self Determination Helps Build Better Lives Better



Accomplishments

The concept of Self determination was first introduced to DDS during the 1990's. Since then many new practices have been put into place in DDS to help people with disabilities have: the **Freedom** to decide how to live their lives; **Authority** over their resources and supports; the **Support** they need to live full lives; and **Responsibility** for their decisions and actions. In the words of the national self advocacy group, Self Advocates Becoming Empowered (SABE), self determination can best be described by the slogan:

“Nothing About Us Without Us.”

Some of the most important new practices that have resulted in changed lives include implementation of the concept of portability, the development of individual budgets, the availability of self-directed services and a greater emphasis on and support for self-advocacy.

New infrastructure supports provided by support brokers, fiscal intermediaries and Self Determination Directors help ensure that opportunities to lead a Self Determined life becomes a reality for greater numbers of people served by the department, over time.

The articles in this newsletter provide a reminder of the supports and services that are available to help people assume greater control and authority over their lives and to attain an improved quality of life.

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Special Thanks to the Individuals Who Shared Their Stories in This Issue

Portability: Freedom Put Into Practice

Portability Means:

- **You have control over your supports and services**
- **If you are not satisfied with your supports and services, you can use the funds allocated to you to purchase different services**
- **Your case manager or broker will help you move your funds when you want to change your supports and services**

In the past, people served by DDS had few opportunities to plan their future and had little recourse when they were not happy with the services they received. They had to rely on others who were in charge of DDS resources to fix their problems and find solutions to their needs.

Today, portability allows people served by the department to take control of their lives. Portability allows people to know what funds have been allocated to them and allows them the freedom to move funds and use resources differently when change is needed.

Successful implementation of portability occurs when an individual:

- ◆ Knows what funds have been allocated to him or her
- ◆ Is informed about the ways that allocated funds can be used
- ◆ Knows how to move funds and is encouraged to do this as a means to help solve their problems, as needed

DDS has developed several resources to help people understand how to use the portability process and to help make informed choices about their supports and services. These resources include the video, "Taking Control of Resources in CT: Portability" and the following three guides that have been written for consumers and their family members:

- ◆ Understanding the CT DDS Home and Community Based Services Waivers: *A Guidebook for Consumers and Their Families*
- ◆ Understanding the CT DDS Home and Community Based Services Waivers: *A Guide to Your Hiring Choices*
- ◆ Understanding the CT DDS Home and Community Based Services Waivers: *Making Good Choices About Your DDS Supports and Services*



Jossie asks... Are you self determined?

Do you know what resources have been allocated to you?

Do you know what supports and services are available to you?

Do you know how you can make your allocated funds portable, if needed?

Portability provides freedom! Know your rights! Know your options!

Individual Budgets: The Foundation for Increased Authority and Control

Portability allows individuals served by the department and their families to know what allocation is available to them and provides the freedom and control to move these funds, as needed. **Portability helps determine who gets the money to deliver the services you want!**



MONEY IS POWER!

Individual budgets provide even greater control and authority by allowing individuals to make decisions not just about which provider will provide services and receive funds, but also about how allocated funds will be spent. Individual budgets allow individuals to make decisions about the types of supports and services to be purchased and allows them to make decisions about specific line items in a budget such as how much an employee should be paid and what benefits they should receive. **Individual budgets allow individuals to determine how the money is spent!**



Authority over how funds are spent increases self determination!

DDS has a responsibility to be a good steward of the money it receives from the federal and state governments. DDS must show that all funds are being used wisely and well. The Level of Need process, rate setting activities, cost standard guidelines and other infrastructure processes are important systems that have been created to help ensure that decisions about funds are made in consistent and fair ways. They also help hold everyone accountable for managing and spending the money that is in their control. **Increased control and authority requires that individuals know and have input into the department's rules that govern their allocations, and they receive the supports they need to manage their funds effectively.**

Varian asks... Are you self-determined?

Are you satisfied with how your allocation is being spent?

Do you feel you have enough input into how your allocation is spent?

Do you get the supports you need to manage your allocation successfully?

Money provides power! Know what you have! Advocate for what you need!



Self Direction: Responsibility in Action

Self Directed Services Means:

- ◆ **You Are in Charge of Finding, Hiring, Training and Managing the Employees Who Support You!**
- ◆ **You Decide What Your Employees Do For You!**
- ◆ **You Decide How Your Allocation is Spent!**
- ◆ **You Work With Your DDS Broker (or Independent Broker) and Fiscal Intermediary to Manage Your Services!**
- ◆ **You Are Responsible!**

Responsibility means knowing your strengths and using these strengths to make your life better. Responsibility means knowing when you need help and being able to ask for and get the help you need to succeed. Finally, responsibility means being part of the solution, rather than part of the problem. This requires balancing personal responsibility, “I can do this myself” with group collaboration, “I’m part of a bigger team, I need to do this with others.”

For a long time, it was assumed that people with intellectual disabilities could not be expected to take responsibility for their actions because of their disability. Self determination helps us to see that all people, regardless of their needs, feel better about themselves when they have greater control and authority in their lives and when they can contribute to the quality of their life through responsible action.

Self-direction, or hiring and managing your own supports, provides the greatest degree of control and authority over services and supports, but with it comes the greatest degree of responsibility. People who choose to self-direct their services have all of the responsibilities that go along with being an employer. They are responsible for recruiting, hiring, training, paying, and supervising the employees they hire. To help make this responsibility easier, DDS has created broker positions, Fiscal Intermediary agencies, and developed other infrastructure supports to help individuals meet their employer responsibilities. Choosing to self-direct your services is a great way for people with intellectual disabilities to show others just how responsible and capable they can be!



Genna asks... Are you self determined?

Do you use your strengths to help make your life better?

Do you ask for help when you need it?

Do you take responsibility for your life by brainstorming solutions to your problems and by collaborating with others to implement your ideas for action?

Self Advocacy: The Best Kind of Support

Self determination means having the confidence to speak up for yourself. It means knowing your rights and speaking out when you think your rights have been violated in some way. It means having the supports you need to communicate your own thoughts in your own way. It means speaking for yourself whenever possible.

Some people with disabilities need help to communicate with others and need help to live the kind of life they want to live. The best kind of support happens when people “Do With, Not For.” This kind of support occurs when support staff:

- ◆ Take the time to really get to know a person
- ◆ Talk less and really listen to the person
- ◆ Provide supports that help the person convey his or her own message and to be in charge of his or her life (Examples- pictures, communication devices, etc.)
- ◆ Helps the person learn self advocacy skills so that they have the confidence to speak for themselves

There are lots of ways that support staff can assist an individual to learn self advocacy skills. They can help the person prepare to participate in their IP meeting. They can help the person participate in a self advocacy group, or attend a self advocacy training or conference. They can provide support so that the person can practice public speaking skills. There are a variety of self advocacy resources available on the DDS Self Advocacy website. All of these materials on this site are written for or by people with intellectual disabilities.



Chester Finn, President of Self Advocacy Becoming Empowered (SABE), a national self advocacy group, and Carol Grabbe, President of CT People First, a statewide self advocacy group for people with developmental disabilities.



The DDS Self Advocate Coordinators ask...

Are you self determined?

- ◆ Do you know your rights?
- ◆ Do you speak up for yourself whenever possible?
- ◆ Do you know how to advocate for yourself and how to advocate for others?

A Day of Respect

Governor Rell declared March 16, 2009 as a "A Day of Respect". To celebrate and honor this day, the Self Advocate Coordinators (SACs) held a "Day of Respect Coffee Break" at noon at their office sites. Each SAC offered free coffee and goodies (while they lasted) at their Self Advocacy table display at noon on 3/16/09. Their table displays highlighted stories relating to respectful treatment of people with disabilities and related topic handouts. Many employees joined the SACs for an opportunity to talk about Respect and what it means to be Respected. Employees learned ways to show greater respect for the people they support.

The SACs remind everyone when supporting people with intellectual disabilities - "Do Not Work On Me, Work With Me!" and "Do Not Tell, Correct, and Lead. Just Listen, Support and Follow." They also offered the following suggestions:

- ◆ Use People First Language
- ◆ Use Plain Language
- ◆ Provide Accommodations When You Want to Include Us
- ◆ Provide Us With The Same Opportunities That You Have
- ◆ Treat Us Like You Would Want to Be Treated Yourself



Vincent Cox at STS.



Varian Salters at the
DDS Willimantic office.

Implied in all of the principles of self determination is the idea that all people with disabilities will be treated with Respect and Dignity. Unfortunately, even with the great gains people with disabilities have made in our society, respect does not always occur as it should. To underscore the importance of Respect, the SACs made a decision to "Make Every Day a Day of Respect". They will do this by keeping a section of their bulletin board available to share ideas on ways to be respectful to people with disabilities every day. Please feel free to use this space to share your thoughts on this important topic.

Lives Well Spent

Two Perish in Wilton Fire– the Untold Story

By Nancy Armstrong

Cynthia Timmons & Dana Conley



The Wilton community was devastated by the tragic fire on February 21, 2009, that resulted in the loss of two fine individuals who happened to have developmental disabilities. The two lives lost belonged to Cynthia Timmons and Dana Conley. The story of Dana and Cynthia is a story of their own design. It is a tale of successful lives, filled with good friends and good family.

Cynthia was a lifetime resident of Wilton, with family roots as deep as those in her grandfather's Wilton apple orchard. She was a recognized and welcomed member of the Wilton community, a sweet, friendly individual with much to contribute. She volunteered for many years, helping the retired nuns at the School Sisters of Notre Dame in Wilton. Cynthia experienced many wonderful things in her life, from travel to education. She was surrounded by a family who not only loved her, but also afforded her the security and confidence to do and be everything that she wanted to be. Cynthia was in charge of her own life; everyone who knew her, knew that.



In 2008, Cynthia found herself living alone in the two-bedroom apartment where she had lived for over 15 years, sometimes with a roommate and sometimes alone. Her family and her support system both agreed that it would be ideal if there were someone living in the second bedroom. Cynthia, however, insisted she was most content living alone and said, "No, thank you," to the idea. Cynthia was happy living with her cat, Sandy, and working at the Village Market in Wilton.

Around that same time, Dana had retired from Schulhof Animal Hospital in Westport where he had worked for over 20 years. Dana had lived in Norwalk, before moving to Westport to be close to his job. He made many friends and he enjoyed traveling. Dana particularly enjoyed trips to New York and Virginia to visit with his family. Dana was very proud of his work, but after he retired, there was no reason to continue to live near his previous job. Dana confided to friends that he was not happy living by himself. He was lonely.

One Saturday, a crew of friends, which included Dana and support staff, decided to drive to the Statue of Liberty. They wound up with an extra seat in the car, so they invited Cynthia along. Cynthia took advantage of that empty seat, fitting into the circle of friends so naturally, that she agreed to join in their activities each Saturday.

Dana and Cynthia had always been friends, but slowly got to know each other even better. Eventually, Cynthia decided to ask her friend Dana to share her apartment. It was a little over one year ago that he and his cat, Susan, moved in with Cynthia and her cat, Sandy.

Dana was a proud man, who insisted on working in order to pay his bills. He frequently said, "I do my best to be a good man." He accepted a job as a member of the Norwalk Mayor's SoNo Crew, through which he enjoyed having lunch with Mayor Moccia. Attending church weekly was very important to Dana. STAR support staff picked him up each Sunday morning for church services at St. Paul's on the Green in Norwalk.

Again, there was an extra seat in the car, and Cynthia decided that she would like to see what the church service was like. After that first time, Dana and Cynthia went to church together every Sunday. Dana's and Cynthia's very busy lives continued with visits to the Museum of Natural History, the Mystic Aquarium, the Maritime Center, the Westport Theater, walks on Calf Pasture and sometimes a quiet evening at home watching TV. Once a week they would visit with Cynthia's mother and aunt to share a pint of ice cream and fond memories.



There is no exact moment when it happened, but one day they looked at each other, smiled, and from all appearances, never again broke eye contact again. Dana felt that after a lifetime of yearning for love, the person who could love him back had been standing right beside him. Cynthia made the decision to give love a try and fell in love with a man as sweet and friendly as she was.

They were in love. You could see it. You could feel it. They began to talk about it. Eventually, Dana asked the STAR staff, "So... how does one go about this getting married thing?" It was suggested that he begin with a proposal and an engagement. Dana figured that was a good plan. He told Cynthia's mother, "I love your daughter, and I want to marry her." Mrs. Timmins understood, because, "Cynthia was certainly lovable." On Valentine's Day, 2009, Dana asked Cynthia to marry him and she accepted. He asked his support counselor to drive them to select a ring. The design Cynthia chose was sent out to be sized.

Each morning Dana and Cynthia kissed each other goodbye before they left for work. On Friday afternoon, the day before the fire, Dana remarked to his support staff, "Isn't it something that after all these years, we would finally find each other?"

Dana and Cynthia are an example of self-determination and dreams realized. Thank you to the Wilton community and to every person who understands that people are all different, but mostly alike.



It seems important that you know about these two remarkable people. We knew their lives were both popular, we knew their lives were rich with family and friends, we knew.

They were involved with the community, but through the heartwarming outpouring of grief and offers of sympathy, STAR and the families continue to appreciate each day how much the community learned, grew and benefited from the presence of Cynthia and Dana in their lives. Cynthia did not get to wear her ring in this life, but she will take it with her on the new adventure that the two have embarked upon together.

We believe that this story shows that self determination does help people to live the life they choose, **and** that there is still much more work to be done. Cynthia and Dana were happy in their lives, were part of their community, lived their dream and benefited from the opportunity to have greater freedom, authority, support and responsibility in their lives. Yet, clearly we have more to learn about how to best support the people we serve.

It is important that we all reflect on how we can provide the people we serve with greater opportunities for self determination while still helping to keep them safe. Successful self determined lives occurs when the people we serve experience the "Dignity of Risk" while also receiving the supports they need to lead safe and healthy lives.

