

A Guidebook on Self Advocacy

SELF ADVOCACY

*CAN HELP YOU
REACH FOR THE
STARS.....*

Created by
The State of Connecticut
Departmental of Developmental Services
Self Advocate Coordinators



October 1, 2007

ACKNOWLEDGEMENTS

This guide was created by the Connecticut Department of Developmental Services Self Advocate Coordinators: Chavis Chappell, Carlos Colon, Carol Grabbe, Genna Lewis, Joyce Rivers, Varian Salters, Jossie Torres and Ivan Villa.

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A Message from the DDS Commissioner



Peter H. O'Meara

The Department of Developmental Services (DDS) believes in and supports self advocacy in Connecticut. DDS's commitment to self advocacy was highlighted by the creation of 10 part-time Self Advocate positions in 2004. These positions were created to assure that consumers have an active role in the development and evolution of the Department's service system. Individuals in these positions are responsible for the following:

- Expanding and enhancing self advocacy in Connecticut.
- Representing consumer viewpoints on agency committees and workgroups.
- Encouraging consumers to have more influence in policy development.
- Enhancing the training provided by the department from a consumer's perspective.
- Creating materials written for, and by, people with developmental disabilities.

The department has also supported self advocacy efforts by incorporating changes into the Individual Planning process to encourage greater consumer involvement. In addition, the creation of statewide and regional Quality Councils now include consumers who continue to give valuable advice about the quality of services provided by DDS.

DDS's Self Advocate Coordinators have become an integral part of the agency. They continue to assist DDS staff within each of our three regions to better understand and apply best practices in self advocacy and self-determination for all individuals who receive services from the department.

A Message from the DDS Deputy Commissioner



Kathryn duPree

Self Advocacy is important to the success of this department. In the Division of Family and Community Services Self Advocate Coordinators provide training, help us with hiring new employees and are part of many decision making committees. They have also started self advocacy groups throughout their regions. They are making videos that we can use for training other people about their rights and the choices they can make about who works for them and provides the services they need. A Self Advocacy Council has been active for the last 4 years advising me and my staff about policy, service needs and the budget.

We also support the efforts of People First of CT which is a strong organization of self advocates. The DDS has partnered with People First in the following ways:

- Helping create People First newsletters which are linked to our website
- Partnering to sponsor self advocacy and self determination conferences
- Providing funds to help consumers attend training events and conferences
- Working together to improve employment and other service areas

We learn a great deal when we work in partnership with self advocates. Self advocates speak on behalf of themselves and others to improve the quality of the supports we offer and remind us of the importance of listening and respecting the individuals we serve.

A Message from the DDS Self Advocate Coordinators



Clockwise: Carlos Colon, Genna Lewis, Joyce Rivers,
Varian Salters, Jossie Torres, Carol Grabbe, Chavis Chappell.
Missing from picture: Ivan Villa

Our goal is to help consumers served by DDS understand the importance of self advocacy and to make sure each person is comfortable speaking out to others. We help create new self advocacy groups and help existing groups to be all they can be!

We hope this guide will result in more individuals participating in self advocacy activities and that more families and providers will help with this participation. Currently, there are twenty-two self advocacy groups in CT with approximately two hundred and fifty individuals participating in these groups. Within five years, we hope that all 164 towns in CT have a self advocacy group and that hundreds more people with disabilities enjoy the benefits of participating in these groups!



An Introduction to Self Advocacy



An Introduction to Self Advocacy by Carol Grabbe, DDS Self Advocate Coordinator

Do you ever feel like you have been treated unfairly because of your disability? Have you ever stood up to someone because of how that person made you feel because you had a disability? Have you ever corrected someone who has used words you don't like when referring to you or your disability? Well if you have, that makes you a self advocate!!

What are self advocates? Self advocates are people with disabilities who stand up for themselves when it comes to any issues they may have. Self advocates use words to solve their problems. They learn how to speak for themselves and work with people to make things better in their lives. When they become confident self advocates, they help other people with disabilities too.

Self Advocacy is all about you!!! It's about you learning your rights and speaking up for yourself. How do you go about doing this? One way is to learn how to speak up for yourself. You can do this by joining a Toastmaster group. Toastmasters is an international organization that helps people to learn to feel comfortable speaking up in front of others. You can learn about Toastmasters by looking at their website or by calling the DDS Self Advocate Coordinators to get more information about this important topic. You can also learn to speak up for yourself by attending your Individual Planning (IP) meeting and letting others know what is important to you, or by attending self advocacy activities such as training events and conferences. The Self Advocate Coordinators can also provide you with useful information about how you can be more successful in your IP meeting and about upcoming training events.

One of the most fun ways of learning to speak up for yourself is by joining a self advocacy group. A self advocacy group is a group of people with disabilities that meet to discuss issues they may have and get advice from others in the group on how to work on the problem(s) they are having. Self advocacy groups also teach you about your rights. Another thing people do in a self advocacy group is support each other. Because everyone in the group has a disability, most of them understand your issues and have probably experienced some of the same things as you. Last but not least, joining a self advocacy group is a GREAT way to make new friends.

There are many self advocacy groups in Connecticut. Some self advocacy groups are very active and serious about their work. Other groups are

more social and recreational. This means that different groups have different focuses, so you have to pick the group that is right for you!

Here is a list of what some self advocacy groups do:

- Learn about your rights as a person with a disability
- Invite speakers to present on topics of interest
- Discuss politics and upcoming elections
- Talk about current events
- Do problem solving as a group
- Give advice to other members
- Write letters to legislators to express concerns
- Educate people about issues effecting people with disabilities
- Speak at forums, conferences, etc.
- Fundraise for group or important cause
- Listen to and support each other
- Participate in recreational activities
- Work on speaking in front of people
- Learn about the best way to approach a problem

Being a self advocate means that your voice is heard! You work to make your own life better as well as the lives of others with disabilities. It is not always easy but it is always worth it!! You get to spread the message that is so important to self advocates: treat us fairly, treat us equally, and treat us with respect. Always, ALWAYS, treat us like people FIRST!!!!



A Short History of the Self Advocacy Movement



A Short History of the Self Advocacy Movement

Written by the National Resource Center on Supported Living and Choice,
Center on Human Policy, Syracuse University

The seeds of the self advocacy go back to 1968 when a Swedish parent's organization held a meeting for people with developmental disabilities. The people at the meeting made a list of changes they wanted made to their services. Over the next five years meetings like this took place in England and Canada. In 1974, a small group of people from Oregon went to one of these meetings, but felt that professionals were in control of it. So, they started to plan their own conference that would be run by people with disabilities. 560 people came and when a second one was held the next year, there were 750 attendees. Within five years, Oregon had 1000 members of self advocacy groups, three different states had growing membership, and people from 42 other states were asking for assistance to start similar groups. Today, the self advocacy movement, as it has come to be known, has grown into an international movement in 43 countries, with an estimated 17,000 members-plus.

In the US alone, there are an estimated to be well over 800 self advocacy groups!



**SABE: A National
Self Advocacy
Group**

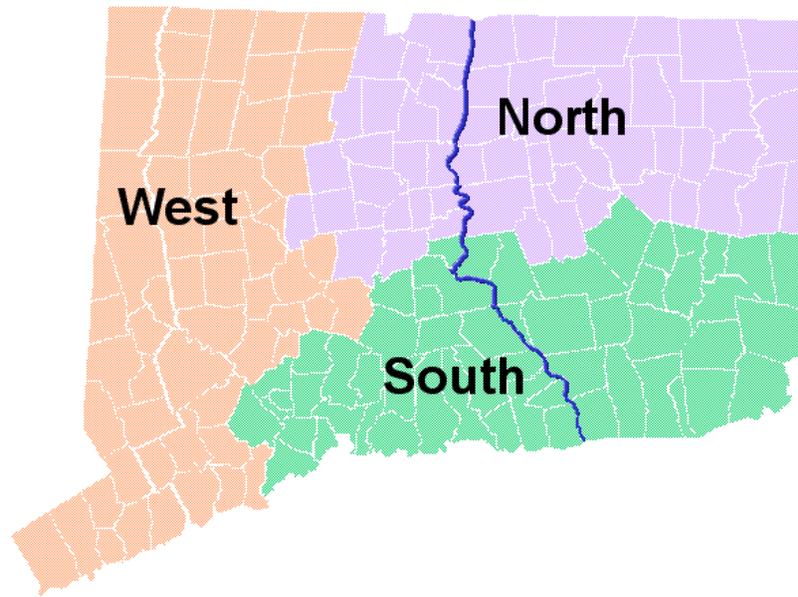


A National Self Advocacy Organization Self Advocates Becoming Empowered (SABE)

The People First movement started in Oregon on January 8th, 1974 at a conference planning meeting. At the meeting one person talked about being labeled “mentally retarded” and said, “I want to be known as a person first!” “People First” was chosen as the name of the convention. Along similar lines, the expression, “label jars, not people!” is often used in the movement to mark a rejection of professional labeling of people with disabilities. Many self advocacy groups call themselves People First of, for example, Canada. But, many groups have other names like, Speaking For Ourselves and Advocates in Action. They are all part of the movement.

Self Advocates Becoming Empowered (SABE) is the US national People First self advocacy organization. It was formed in 1991 and describes itself as an “active organization that is like a family.” It has 18 elected board members who meet four times a year in different cities. Some of the things that the board does to forward the movement include: *Advocacy Action*-keeping members up-to-date of various advocacy opportunities; *Self Advocacy Development*-supporting people who want to find out more about self advocacy and start state organizations; and *Public Relations*-putting out newsletters, membership information, making videos, and recently a music CD, “Songs of the Self Advocacy Movement-RESPECT”.

You can learn more about SABE at <http://www.sabeusa.org>



Connecticut Self Advocacy Groups



People First of CT

People First is a CT corporation and has a 501 c3 designation from the Internal Revenue Service. It was founded in 1989. People First chapters exist in many major cities and towns, and have support from advisors who work for the Department of Developmental Services and The ARC CT chapters and volunteers. People First of CT State meetings are held every other month on the 4th Thursday in a rotating location at 7:00 p.m. The Board of Directors meeting is held on the alternate month on the 4th Thursday at The Arc of Southington from 6:00 – 8:00 p.m.

The original resolutions passed by members in 1990 are now the member's Beliefs Statements, they are as follow:

- Close Southbury Training school
- The Right to meaningful purposeful jobs and close the workshops.
- To Change the name of the Department of Mental Retardation.
- Expand self determination.
- Increase community homes.

People First of CT Mission Statement

The People First mission statement was created in 2007. This statement reads as follows: “People First of Connecticut is a statewide self advocacy organization that believes that ALL people, with and without disabilities, should be treated equally and respected for their abilities. We work together to make positive changes for people with disabilities. We encourage and advocate for choice, independence, freedom, respect, and dignity for EVERYONE.”

Members of CT People First have had a long association with SABE -the national People First association and are proud of the contributions they have made to this organization. TJ Monroe, the first President of CT People First, was on the first SABE Steering Committee. Keira Williams, another President of CT People First was elected to the SABE Board of Directors and served six years. Jean Bowen advisor to CT People First has been a national advisor to SABE for the last six years and Chad Sinanian is currently serving on the SABE board. An impressive role by our CT self advocacy leaders!

For more information about People First of CT contact Jean Bowen, Advisor (203) 788-3156 cell, or send an email to: <http://www.wecahr.org/people>



Kids As Self Advocates (KASA)

What is KASA?

KASA is an organization for youth, run by youth. We help kids with disabilities, their siblings and peers, learn how to be self advocates through information and support. Through the years, we have received support from the CT Council on Developmental Disabilities and the CT Youth Leadership Project. Currently we are housed at the Office of Protection and Advocacy for Persons with Disabilities. We use meeting space at two Independent Living Centers in the state and are always looking for new organizations to partner with. Our membership has grown to include over 35 members and we maintain our connection with the national KASA group through our website, email and teleconference calls.

What does CT-KASA do?

- Allows youth to address topics they feel are important through support & information.
- Provides an avenue for youth to educate society about issues concerning youth with a wide spectrum of disabilities
- Helps other people in the community understand what it's like to live with special health care needs
- Helps youth with special needs and their friends become self-advocates

Anyone between the ages of 13 and 24 is welcome to join us! We are always looking for new members who want to socialize, have new ideas, want to learn how to help themselves and want to educate others. To join us, contact us at: <http://www.ckasa.org/> 860-297-4316 Voice 860-297-4380 TTY 860-566-8714 Fax, 60-B Weston Street Hartford, CT 06120-1551 



CT YLP, Inc.

The Connecticut Youth Leadership Forum at UCONN. The Connecticut Youth Leadership Project (CT YLP) is a youth leadership program that empowers youth with disabilities to realize their leadership potential. Through self-awareness and team building activities, young adults explore leadership styles and develop and implement team and personal leadership plans.

Our goal is to help youth with disabilities meet the challenges of the future, overcome obstacles and become leaders so that they can make a difference in their communities and for others with disabilities.

Our primary way of meeting our goals is through the Connecticut Youth Leadership Forum, a week-long leadership program that is held every July at UCONN. At this forum, young adults who have a variety of disabilities learn advocacy and leadership skills through participation in small group activities, outdoor team building games, and large group events. Although CTYLF is not a self advocacy group it is an important resource for building advocacy and leadership skills.

You can learn more about CTYLP at <http://www.ctylp.org>



Disability Advocacy Collaborative (DAC)

The Disability Advocacy Collaborative is a coalition of cross-disability activists who work together to empower and support people with physical and mental disabilities in Connecticut. The mission of the Collaborative is to enhance the effectiveness of disability activism by organizing and empowering individuals, families, groups and organizations.

The Disability Advocacy Collaborative strives to improve communication between and among disability groups, collaborate with other disability advocacy organizations, activate and mobilize individuals with disabilities, and educate it's membership. Key DAC activities include the following:

An E-Newsletter: The Bulletin, a monthly newsletter, includes state news of interest to advocates, and updates on activities undertaken at the national level. A calendar of events is also published monthly, at the beginning of each month.

Monthly Meetings: Monthly DAC Board meetings are held to create a more unified voice among disability groups, which results in a stronger advocacy base.

E-Alerts: E-alerts are sent out to all members of the Collaborative with time-sensitive information that needs follow-up action; for example, there may be a legislative proposal that requires input from the various disability groups.

Education Activities: A variety of educational opportunities are periodically offered by the DAC. Educational opportunities range from basic advocacy training, to leadership training for future disability rights leaders, and training that provides information to better inform legislature and policy-makers.

The DAC also does its work through regional self advocacy groups. To get involved with a Regional Advocacy Network, contact the following:

- **Northwest** — contact: Bill Knight (lackerman01@snet.net)
- **Southwest** –contact: Carol Kana (pkana@snet.net)
- **Danbury Area** — contact Pam Arturi (parturi@abilitybeyonddisability.org)
- **North Central** — contact: Candace Low (clow@independenceunlimited.org)
- **Waterbury Area** –contact: Mike Valuckas (mike.valuckas@independencenorthwest.org)
- **Northeast Area** – contact: Carolyn Newcombe (cnewcombe@charter.net)

DAC encourages people with intellectual disabilities to join these cross-disability advocacy groups. Your participation is a great way to help other's hear the united voice of people with intellectual disabilities and to develop advocacy leadership skills.

You can learn more about DAC at <http://www.ct-dac.org>



Local Self Advocacy Groups in CT



Local Connecticut Self Advocacy Groups

There are currently twenty local self advocacy groups in CT. These include People First local groups, DDS sponsored local groups, and groups supported by private agencies. The local groups are located in the following towns:

[Bristol](#)

[Danbury](#)

[East Hartford](#)

[Enfield](#)

[Farmington](#)

[Manchester](#)

[Middletown](#)

[New Britain](#)

[New Haven](#)

[New London](#)

[Norwich](#)

[Putnam](#)

[Southington](#)

[Southbury](#)

[Torrington](#)

[Wallingford](#)

[Waterbury](#)

[Willimantic](#)

The goal of the DDS Self Advocate Coordinators is to have a local self advocacy group in every town in CT! **146 towns to go!**



People First of CT Local Chapters

Bristol – Starlite

1st Thursday – Oasis Restaurant

3rd Thursday – Polish-American Club

Michelle Brock, Advisor michelle.brock@po.state.ct.us

860 263-2576 or 860 314-0663

Danbury – People First of Danbury

3rd Thursday – Ability Beyond Disability

Pam Arturi, Advisor parturi@abilitybeyonddisability.org

203 826-3089 or WeCAHR 203 792-3540

Enfield – Together We Can

4th Wednesday every other month at Allied offices

Ed Lamontagne, Advisor Elamontagne@alliedgroup.org

860 229-6665 x159

Manchester – Marc Chapter

3rd Tuesday – MARC, 376 Middle Turnpike Road (Parkade)

Peter Englebrecht, Advisor penglebrecht@marcct.org

860 646-5718

Middletown

Self Advocates Unlimited

3rd Wednesday – First Church of Christ, Court Street

Carol Grabbe, Contact carolgraytb9@sbcglobal.net

860 347-3083 (h)

Middletown

Guardian Angels

1st and 3rd Wednesdays – MARC, 421 Main Street, Cromwell

Laura Hastillo, Advisor Laura.Hastillo@marc-cr.org

860 342-0700 x14

New Britain – Yes I Can

Meetings every other Tuesday @ New Britain City Hall

Anna Cardona, Advisor acardona@ccarc.com

860 229-6665 x159

Putnam – People Meeting People East

Killingly Library, Denise Gingras-Sondak

Denise.Gingras-Sondak@po.state.ct.us

860-630-3823

Southington

1st Tuesday except July & August – Mulberry Gardens, Plantsville

Mike Ruzzi, Contact mikestretch@cox.net

860 621-0020

Southbury Training School – Up With People First

Every Wednesday 4:00 – Fleck Hall

Jeanne Braude-Magi 203 586-2954 – jmbraude@sbcglobal.net

Or at WeCAHR 203 792-3540

Torrington – Each One – Teach One

2nd Tuesday 6:30 – LARC-DSO Building, 66E Albert Street

Robin Pedone, Advisor rpedone@litchfieldarc.org

860 489-2140 x14

Willimantic – People Meeting People West

3rd Tuesday

Claire Lary, Advisor Claire.Lary@po.state.ct.us

Varian Salters, Contact Varian.salters@po.state.ct.us

860 456-6345 (o)



DDS

DDS Sponsored Groups

East Hartford

Name of Group:

Meeting Dates: 3rd Monday of the month

Contact Person: Chavis Chappell chavis.chappell@po.state.ct.us

Phone: 860-263-2529

Farmington

Name of Group: ***United Voices***

Meeting Dates: 1st Thursday of the month, @Canton Parks and
Rec. from 4:00-6:00 pm

Contact Person: Carlos Colon carlos.colon@po.state.ct.us

Phone: 860-331-2072

New Haven

Name of Group: ***Dream Team***

Meeting Dates:

Contact Person: Genna Lewis genna.lewis@po.state.ct.us

Phone: 203-974-4225

New London

Name of Group: ***Sea View***

Meeting Dates: 1st Tuesday of the month, President Sharon Spiegel

Contact Person: Joyce Rivers joyce.rivers@po.state.ct.us

Phone: 860-859-5442

Wallingford

Name of Group: ***Hearts That Care***

Meeting Dates: 2nd Tues. of every month from 5:30-6:30

Contact Person: Carol Grabbe carol.grabbe@po.state.ct.us

Phone: 203-294-5119

Waterbury

Name of Group: ***Advocates Taking Charge!***

Meeting Dates: Thursdays from 5:30-7:00 pm

Contact Person: Jossie Torres jossie.torres@po.state.ct.us

Phone: 203-806-8736

And an independent private agency sponsored group....

Norwich

3rd Thursday 5:30 pm - New London County Arc, 125 Sachem, Norwich

Lori King, Advisor lking@thearcnlc.org

860 889-4435 or

Joyce Rivers, Contact joyce.rivers@po.state.ct.us

860-859-5442



New London ARC Self Advocacy Group Officers
Ed Boyko, Aaron Newton, Karen Montgomery and Jessica Clark



Self Advocacy Resources

Self Advocacy Resources

ACT (Advocating Change Together)



Email: act@selfadvocacy.org

1821 University Avenue W Ste 306-S

St. Paul, MN 55104

Telephone: 651-641-0297 or 800-641-0059

FAX: 651-641-4053

Act Self Advocacy Resource Network is a clearinghouse for materials and training that support self advocacy. The ACT MEMO is an online memo which provides advocacy training and facilitates a national dialogue among self advocates and their supporters.

The Riot



<http://www.hsri.org/leaders/theriot/>

The Riot is a national E-Newsletter from the Self-Advocate Leadership Network@ HSRI.

Disability World



<http://www.disabilityworld.org/>

A web-zine of international news and views.



P.S.

**How Providers,
Family Members,
Friends and Allies
Can Help Support
Self Advocacy**



How Can You Support Self Advocacy?

Help individuals learn about self advocacy. Individuals need information to make informed choices. The more information provided to people with disabilities, the more likely it is that individuals will learn to advocate for themselves. It is important that you remember to provide information in ways that accommodate people's learning needs.

Assist individuals to advocate for themselves on a day-to day basis.

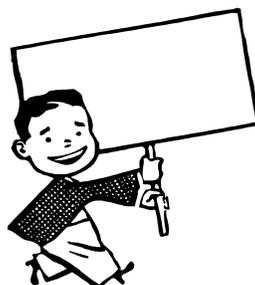
Practice makes perfect. The more opportunities for self advocacy experiences, the greater likelihood that people will obtain and maintain their advocacy skills. Self advocacy can be practiced when people are allowed to make choices, including saying "NO!"; when they are allowed to assume responsibility and take informed risks, and when they are included as active members in decision-making activities.

Assist individuals to advocate for themselves at their Individual Plan (IP) meetings. It is very important that people advocate for themselves at their individual planning meetings. Helping individuals to prepare for participation and leadership at planning meetings is a wonderful way to help support self advocacy skill development. You can help individuals send out invitations to meetings; help individuals prepare to communicate their wants and

needs at their meeting, and help individuals to brainstorm ways they can help make their meetings more productive.

Assist individuals to participate in advocacy groups. There's nothing like peer-to-peer learning. All of us learn best from people who we feel share similar backgrounds and experiences. Self advocacy groups provide a forum for this peer-to-peer learning. Most people with disabilities need support from others to get to and from meetings. Some people also need support to participate in meetings. Still others need support to apply what they have learned at meetings in their daily lives and to carry out responsibilities they've agreed to at a meeting.

Help develop self advocacy leadership. Many advocacy groups often need advisors to help meeting participants stay on task and keep the group going. Other groups need mentors to help leaders develop their skills. Self advocacy leadership skills can also be developed by helping individuals participate in Toastmaster groups, in volunteer activities such as DDS Quality Councils, or through participation as members of a Board of Directors. Helping individuals participate in learning events is also an effective way to help individuals develop advocacy and leadership skills.



**What are your next steps
for supporting self advocacy?**

You can contact a self advocate coordinator in your area for more information

CALL US!

WE WANT TO HELP!

Varian Salters - 860-456-6345



(Willimantic Office)

Chavis Chappell – 860-263-2529



(East Hartford Office)

Carlos M. Colon – 860-331-2072



(Newington Office)

Joyce Rivers - 860-859-5442



(Norwich Office)

Carol Grabbe – 203-294-5119



(Wallingford Office)



Genna Lewis-203-974-4225

(New Haven Office)



Jossie Torres – 203-806-873

(Cheshire Office)



Ivan Villa 203-806-8830

(Waterbury Office)

(Torrington Area- Position Pending)