

Self-Advocacy News



December, 2001



"Carrying on together" Self-Advocacy and September 11th.

Canceling our annual conference was probably the hardest decision the Board of Directors of

Self-Advocacy has ever made. We had 800 conference packets and all materials packed away ready for 800 guests to arrive at the Marriott Hotel. We were in full conference mode when the tragedy struck New York.

In the discussion about whether to cancel or not, one of our board members said, "we can't let these terrorists decide whether we have a conference or not. We have to go on with our work." This noble thought got a lot of attention in the discussion but in the end, the decision to cancel came down to three factors: 1) many of our friends from the NYC and Long Island were not going to be able to attend; 2) so many people were in shock and mourning in our country, it just didn't seem right to have a

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Share the Spirit - Shuffle Off to Buffalo by Clint Perrin

Hello everyone! I am Clint Perrin, Chairperson of the 2002 Share the Spirit

Conference. We are very excited about this event. While we are sad we had to cancel our statewide conference due to our national crisis, we are committed to organizing a great conference in Buffalo. There is no better time than now to Share the Spirit. Inside this newsletter you will find information about the conference and answers to some of your questions. On our web site, sanys.org, we will be posting more information as it becomes available. You can also download copies of our brochure to share with your friends.

It takes lots of people to plan a national conference and we will have lots of help. We have three basic committees at this point. Our Logistics Committee is based out

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celebration, which is what our conferences are; and 3) people simply needed to be close to home and their families.

What the Board decided to do was not reschedule the conference, but focus on our regional conferences and our national conference on September 19-22, 2002. For NYC we decided to have a day of reflection and celebration which we titled, "Carrying on together, a day of hope and reflection".



Without a doubt our country changed a lot on September 11th. We see the changes in a big way in war, in our airports, and in the fear, strength and sacrifice we see among our fellow citizens each day. Other changes are coming and will affect our work and advocacy. The US and world economy is in decline right now. States like NY face tough budget problems. There will be less funding available for supports and services. We'll all need to pull together and decide just what is important, what are the key things for organizations like SA to focus on.

We also need to work together to help each other deal with the fear and challenges that have come in the aftermath of the September 11 attacks. But that is what self-advocates do best, help each other. What are your thoughts on all this? How can SA support our members, how do we best advocate for our important issues like jobs, people's own homes and self-determination in these difficult times? What are your thoughts on these issues? Write us or call the SA office.

In this newsletter, you'll see a list of strategic goals for the coming year. What are the most important things for SA to work on? We need your thoughts and ideas. Write us or call the SA office.

Have a wonderful and peaceful New Year!

The Board of the Self-Advocacy Association of New York State.

Shuffle off to Buffalo cont. from Page 1



of Buffalo and that group will work on a lot of the Buffalo based details and arrangements for the conference such as registration at the conference, volunteers, transportation, decorations etc. This group will also work on Buffalo based fundraising. That committee is chaired by two SA Board members John Fritz and Donald Chrisman. We have a great group of committee members helping with these plans.

The Program Committee is chaired by Chester Finn and will be meeting out of the Albany area. The Program Committee will be responsible for organizing the conference activities and programs such as entertainment, key note speakers and workshops. We will have some exciting events at this conference including some Town Meetings in which self-advocates will speak up about issues that our important to us directly to some national leaders from Washington.

Our Fundraising Committee is also working out of the Albany area. I am working with Steve Holmes, our Administrative Coordinator and some other volunteers for this committee. We have two strategies that we are working on. First is to raise money to help us reduce the cost of attending the conference and secondly we are trying to find ways to help people who want to attend to get scholarships and/or support from organizations within their state. September 11 has made our work harder as money is very tight across the country right now.

We are excited to tell you that the Administration on Developmental Disabilities in Washington has made a commitment to give us \$50,000 in scholarship funds which is a big boost to our efforts. But there is much more work to do. We know the conference is going to be expensive so we encourage you to start raising your own funds and getting whatever support you need to attend lined up.

We hope to have 1200 people attend this conference and we hope at least 400 will be from New York.

Self-Advocacy Association of New York State, Inc.

Our dream for our organization:

Drafting our Strategic Plan--September, 2001

On August 13th and 14th, 2001, the SA Board of Directors met to begin the process of strategic or long term planning. We know how important it is to have a dream and a vision for our lives and it's also important we have a dream and a vision for our organization.

At our planning retreat we used a way of planning called SWOT. SWOT stands for **S**trengths, **W**eaknesses (areas for improvement), **O**pportunities and **T**hreats (things that will challenge our organization now and in the coming year). It's a planning exercise that a lot of organizations do. After the SWOT process we then began thinking of some goals for the year 2002 and for the years 2003 and 2004. For this process, we are looking at our statewide organization not any individual or regional goals. We are developing this plan so we can accomplish our organization's goals and mission.

We started with our mission statement. After some discussion, the board unanimously agreed that our 1994 vision and mission statements are still valid today. The board officially affirmed these statements (see box) as the current vision and mission statement of SA.

In the following pages you'll find a list of things we discussed at this meeting. We'd like your feedback. What are the strengths and areas we need to improve on? What are the areas or issues we should work on in the

future? What are the challenges facing our organization? What should be some of our goals? We need your help. Let us know what you think.

The Self-Advocacy Association of New York State, Inc. Vision Statement

The Self-Advocacy Association is a strong voice for and by people with disabilities, promoting independence, empowerment, leading by example, communicating, networking and encouraging each other.

Mission Statement

The Self-Advocacy Association of NYS is an organization for and led by people with the challenge of a disability to assure the civil rights and responsibilities that include the opportunities and choices of equal citizenship. The association accomplishes this by:

- * educating
- * advocating
- * networking
- * sharing information and resources
- * promoting respect and dignity
- * improving quality of life
- * communicating
- * supporting

Adopted by the Self-Advocacy Board of Directors on November 17, 1994.

Affirmed by the Self-Advocacy Board of Directors on August 13, 2001



Some people think self-advocates are trying to turn the "system" upside down. Well, first, we are the "system" and yeah, we are trying to turn things upside down. The "system" looks a lot different from this point of view, don't you think?



Overview of current projects and activities we've already made commitments to for the next few years.

Current Funded Projects:

- * *Grass Roots Organizing Program (GROP)*-- This is the basis of our self-advocacy work, supporting local and regional groups and our statewide board and organization.
- * *AmeriCorps*, "Our experience is the best teacher"--Up to fifty nine members are supported to give presentations to staff of agencies, schools and community organizations. Currently funded by The National Corporation on Community Service, OMRDD, and VESID.
- * *Self-determination*--We are currently finishing a project funded by DDPC that has helped develop the first opportunities for self-determination in New York State. We are applying for additional grants to continue to work on self-determination issues.
- * *Medicaid Service Coordination Project*-- We are teaching service coordinators and self-advocates about Medicaid Service Coordination and how the role of the service coordinator is to work for the person.

Significant Activities we've committed to for the coming year.

By significant we mean projects and activities that require a lot of our time and financial resources.

- * *2002 National Conference*--We are sponsoring the 2002 National Self-Advocacy Conference in Buffalo in September of 2002
- * *System Change Project Proposal*--For this project, self-advocates will visit people living in large group living situations and teach

them about their options for more integrated living. This project is related to the Supreme Court Decision that gives people with disabilities the right to live in the most integrated setting possible.

Other Project and activities that we have said we will focus on include:

- * *NYS CARES follow-up*, help insure people have individualized choices
- * *Focus on transportation issues*
- * *Create a self-advocate driven organization called COOL: Creating Our Own Lives*
- * *Day Services & Work issues*
- * *Getting people on Boards & Committees,*
- * *Keeping up with national issues and supporting our national organization Self-Advocates Becoming Empowered*
- * *Increase legislative activities related to our goals*
- * *Leadership Development*
- * *Advisor Development*
- * *Staff and organization development and improvement*
- * *Continue to participate in as many conferences, committees, councils and planning groups as possible*

2001-2002 Goals

1. Continue the four current projects we have and keep improving on this work.

2. Complete a grant application to fund continuing self-determination work but focus on helping people involved in the next pilot process to be successful--develop training curriculums on circles of supports, individual budgeting and person centered planning. Help individuals develop their goals, expand their circles and develop successful proposals for individual funding through self-determination

3. Continue involvement with projects and activities we listed in this document that related to commitments or initiatives we've already made, including our national conference in Buffalo.

4. Reorganize our staffing structure

*Develop a second in command position to work with the administrative coordinator to help oversee our funded projects and activities and support the board's work.

*Where possible develop some full time regional organizing positions by linking grant activities and responsibilities--AmeriCorps and GROF for instance

5. Strengthen our regional teams (Board, staff, advisers, and AmeriCorps members)

*Meet twice per year

*Recruit two regional advisers to support our regional efforts

*Ensure that each region has one statewide adviser who supports regional board members to attend and participate in meetings

6. Participate in Legislative Day in February of 2002

7. Revise our By-Laws

Some longer term Goals: (2002-2004)

* Expand AmeriCorps Project

* Develop Vista Grant

* Consider smaller regions

* Hire full-time regional organizers in each region

* More support staff

* Significantly increase fund raising and non government grants

A Message from the SA Board

Well now you have some idea about what we hope to be working on. We put these goals together based on what we've heard from all of you over the past few years. Now we need your help.

Please let us know what you think of our draft plan. Are there other things we should be working on? We want to hear from you. To see more about our planning process including a list of what we think are our strengths as an organization and the things we need to improve on, go to our web site at sanys.org and see a summary of the entire planning meeting.

If you have any questions or suggestions call Steve Holmes 518-382-1454.

With team work we can achieve all our goals together. Even when it seems we're trying to push a giant, heavy ball up a mountain. TEAM stands for Together Everyone Achieves More





Share The Spirit Shuffle off To Buffalo September 19-22, 2002



Q: What is **Share the Spirit**?

A: **Share the Spirit** is the 6th National Self-Advocacy Conference. It's the conference for Self-Advocates Becoming Empowered (SABE) that's held every two years. SABE is the National Self-Advocacy organization. Self-Advocacy Association of NY, Inc. (SANYS) is the host of the 2002 conference.



only \$99 plus tax per night. Up to four people can share the room -- no added charge!

Q: Will scholarships be available?

A: Yes, some scholarships will be available, but we do not know how many and for what amount. We are working hard to raise funds so we can offer a lot of scholarships. Information will be mailed when we have it.



Q: When is **Share the Spirit**?

A: **Share the Spirit** begins on Thursday, September 19, 2002 with an opening ceremony in the evening. It runs through Sunday, September 22, 2002.

Q: What are the planned workshops?

A: Workshops have not been decided yet. In the next few months we will be sending out a "call for presenters". If you are interested in presenting a workshop, you can fill that form out. Watch your mail in February, 2002.



Q: Where is **Share the Spirit**?

A: **Share the Spirit** will take place in Buffalo, New York. It will be held at the Adams Mark Hotel.



Q: How do I get to Buffalo, New York?

A: You can get to Buffalo by car, bus or train. You can also fly into the Buffalo-Niagara International Airport. Buffalo is uniquely situated and extremely accessible, being within a 500 mile radius of 55% of the US population.



Q: How much does it cost to attend?

A: At this time, we are estimating the cost to be \$300 per person for the four-day event. This will include 7 meals and all conference expenses. (We are working to raise funds so we can lower the cost of the conference.) It does NOT include hotel cost. Please note: Everyone who attends the conference must pay the registration fee. This includes self-advocates, presenters, family members and support staff.

Q: Will there be a trip to Niagara Falls?

A: Yes, we are planning a trip to Niagara Falls. It will take place on Thursday, September 19, 2002, before the conference begins. The cost for this trip is still undetermined. This trip will not be included in the conference registration. If you plan on attending, you will



Q: How much does the hotel cost?

A: We have received a great hotel rate of

need to pay extra for this trip. As this trip will be going to Canada, a birth certificate and/or a picture ID will be required to take this trip.

Q: How do I find out more information?

A: If you received this newsletter in the mail, you are on our mailing list. We will send you more information when it becomes available. If you picked this up at a meeting or got it from a friend, send us your address. We will put you on our mailing list. If you have an email address, and would like to join our



egroup, send an email request to sanys@capital.net

Q: How do I contact you?

A: You can call us at 518-382-1454, E-mail us at sanys@capital.net, visit our web page at www.sanys.org or mail us at SANYS, 500 Balltown Road, Schenectady, New York 12304.



Conference Highlights

Self-Advocates Becoming Empowered
National Meeting and Elections



Key Policy makers from Washington Invited

Town Meetings to discuss issues important to you...employment, housing and self-determination



Actress/Motivational Speaker
Andrea Friedman

Workshops on the following topics:
National Issues, Self-Advocacy, Housing, Employment, Self-Determination and Community



Music, dancing, see old friends, make new friends!



Here is when more information will be available about the conference...



Mark your calendars, check your mail or our web page at www.sanys.org

January
March
May
July
September

Call for Presenters will be mailed
Presenter proposals due back to us
Registration packet will be mailed
Registration and payment due
Shuffle Off to Buffalo





SA Board Update

by Donald Chrisman

At the time of this article, I am the acting board President due to some of the changes on the board that I am going to tell you about.

A lot is happening with the Self-Advocacy Board this fall. First of all, some of our key leaders are stepping down from the board to become AmeriCorps Members. Tony Phillips, president for the past two years, Clint Perrin, the most recent immediate past president, and Val Findanque, last year's co-vice president have all become full time AmeriCorps members and will be doing a great job in their regions speaking about self-advocacy in schools, at agencies, and in the community. But we have not totally lost their expertise. All three will be attending board meetings this year as mentors for our new board members and leaders. I know I will really appreciate their continued wisdom and support.

To Tony, Clint and Val we send out our best wishes for success with their AmeriCorps work and lots of thanks for all the great work they did as board leaders.

We also have some new members from other regions. From the Central region we welcome Dan Cuddy and Mark Richardson, who were elected in a tight race held at the October Central Region Conference. While we are happy to excited to welcome Dan and Mark, we are sad to say goodbye for now to Ed Palumbo, who came in a close third. Ed gave a wonderful and generous speech in support of the new members and a promise to run again next time. Good luck Ed. We also say goodbye to Karen Case, who decided not to run for another term. We'll miss you Karen!

In the Capital District, Kevin Ryan won another hotly contested election at the June Capital District Conference. Congratulations

Kevin. We said goodbye for now to Melissa Rose. Melissa was appointed to our board for a short time to fill a vacant spot. Melissa promised to run again next year! Best of luck Melissa. The Board also appointed Mike Northrup from the Sunmount area to fill the remaining two years of a board position that became available when a board member stepped down this past year. Good luck Mikel!

In the Hudson Valley, Sharon Hager, won yet another close election to fill the position Val Findanque held. Sharon is a former AmeriCorps member and we look forward to all the energy she will bring to our group. The Board also appointed Barry Zander, who was a runner up in the regional election to fill the last year of a board position that was open due to a board member resigning this past year.

You will see a lot of great articles in our newsletter. We've got a lot of information about awards that we would have given out at the conference that we had to cancel in September as well as thank you to people and agencies that contributed to our Souvenir Journal. Thank you all again.

We also have a copy of the draft of our strategic plan and we are looking for your help. What do you think of our plan so far? Do you have any thoughts, suggestions or ideas? If you do, call, mail or email them to Steve Holmes, our Administrative Coordinator. See the back cover for address, email and phone information.

After what happened on September 11th, we know this will be a challenging year for all of us. On behalf of the SA board, I want to wish you a very Happy New Year. I promise we will all work hard together on your behalf.



**2001 Conference Souvenir Journal Participants
Thank You!!!**

Self-Determination is Our Dream - Self-Advocacy is the Way!
UCP Of Great Suffolk FREE

Crystal Run Village CDDSO-Board of Visitors	Getting The Life You Want AHRC	Northeast Career Planning Albany Marriott
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People, Inc The Resource Center	Speaking For Ourselves NYSDDPC FLDDSO	Schenectady ARC Rensselaer ARC
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CPA Of Rochester Irwin Siegel Agency Lifespire	Don't Just Say It, Do It!!! UCP NYC CNYDDSO TDDSO	Center for Family Support Warren-Washington ARC Independence Residences
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Vincy's Printing Gateway Community Modern Arts Packing Greystone Programs Onieda-Lewis ARC Westchester Medical Center	Our Voices Count NYAPARS Enable AHRC FEGS Liberty Job Path	Guild for Exceptional Children Opportunities Unlimited Advocating Change Together The Advocacy Center Prospect Child & Family Center Community Living & Advocacy
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Leisure Time Programs Susan Richardson CH Energy Group, Inc. Ulster-Green ARC Jefferson Rehab ARC of Monroe The Greenwald's	Nothing About Us Without Us AIM/AUTO SAC UCP WNY CAP UCPAWNY YAI Carol Berrigan Dennis Pflieger	The Guild Esperanza Center Onondaga Community Living Dominican Spiritual Life Center Madison-Cortland ARC REHAB Programs Catholic Charities
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AnnMarie Foley Orange County SA Group Donald Shumway	Walk the Talk Janet Austin The Holmes Eileen McCue	Cantalician Foundation Fingerlakes AC Team Laurie James
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2001 Self-Advocacy Awards

Self-Advocate of The Year
Sharon Hager

Self-Advocacy Group of the Year
Brooklyn Day Hab

Advisor of The Year
Carrie Fisher

Agency of The Year
Rensselaer County ARC

Media Award
Self-Advocates Becoming Empowered
Self-Advocacy Tool Kit



Goodbye...

This is the time of the year that we say goodbye to our outgoing AmeriCorps Members. Thanks for all your hard work and dedication to SA AmeriCorps! Best of luck to each and

everyone of you!

Jeff Alonge
Jennifer Bates
Michael Cardella
Raymond Garcia
Sharon Hager
Emily Judge
Jack Lillibridge
Billy Mitchell
Rose Ostrander
Pam Porter
Andrew Rivers
Jason Sloman
Henry Wesley

Sherry Astor
Barbara Cardella
Sharon Davis
Laurie Graves
Ann Hollenbach
Lunetha Lancaster
Leah McNeely
Wendy Orzel
Corey Ostrom
Wanda Rivera
Covert Shephard
Jay VanLandingham
David York

Welcome 2001/2002 Members!

While we say goodbye...we also say welcome to our 2001/2002 AmeriCorps Member. Lets go out and get things done!

Abike Anderson
Tia Bharath
Chris Bucelli
Ricky Colon
Tammy Dalaba
Dan Dayley
Duane Drake
Val Fidanque
Anthony Galatro
Denise Grimes
Tomekia Hill
James Jesenski
Daniel Kipp
Trina Lipke
Jennifer Machucki
Beth Millard
John Mulligan
Larry Owens
Clint Perrin
Terri Pollack
Jack Rennie
Rain Rippel
Scott Robertson
Helen Scavuzzo
Dawn Smith
Joni Strahen

Andrew Bell
James Brown
Sandra Cobb
Troy Cuison
Alan Dawes
Ginger DeStevens
Tim Elliott
Tamelia Fritz
Marilyn Gill
Kimberly Hennen
Donovan Holmes
Anthony Jordan
Nancy Leandro
Mariam London
Sam Mattle
Jean-Richard Mehu
Carol Owens
Angela Pepper
Tony Phillips
Bill Reed
Teresa Rhodes
Sophia Roberts
Chris Rosa
Stephanie Schwartz
Jason Smith
Tom Wienckowski

Take your wings and fly

by Wendy Orzel

Life is wonderful life is free life is what you make it to be that's the general sentiment into today's world that anyone can be anything but with a disability is this so

We all want to live, work and be a neighbor without the added baggage caused by the ramp or the cane that guides people through the mud, rain or snow

It's your inner beauty within thee the world is filled with opportunity for you to see so don't let your disability affect your ability too succeed

Today you have to lead to make life better for those who follow you have the power to make today's dream a reality for tomorrow

One must have courage to make it through life's journey don't be afraid if your wings start to bend courage is not a matter of doing right or wrong and will take to the journey end

Sometimes we wonder when will we be able to fly keep reaching for the sky and when you feel ready then you take your wings and fly

You must not forget no matter what happens in a persons life just always remember you're not alone because at the end there will be someone there who cares.



Capital Region AC Training
Standing: L to R, Beth Millard, Tony Lamena
Sitting: L to R, Daniel Kipp, Terry Pollack, Rain Rippel

Self-Advocates & September 11th

The following are poems and songs written by self-advocates in memory of the victims of the 9/11 attacks.

2001 September 11

Dora Becker

I remember Pearl Harbor
How many of our young men and women
Died off the coast.
At that time, I was much younger
That was in 1942
It was a terrible experience.
We were watching a football game on a Dupont television
This happened in the West Coast
New York is three thousand miles away.
Everybody said it can't happen on USA soil
But it happened sixty years later.
September 11 the phone started ringing
Every TV was on couldn't believe our eyes
They say two jets crashed into the World Trade Center.
I was there after the crash
I interviewed a lady that was there
She didn't have to tell me how terrifying it was.
I take my hat and everything else off
To the large amount of people who perish in this awful
tragedy.
New York will come back.
It may tak a while
But we will be back!

We watch the City



Chester Finn

We watch the City fall down
But we pick it up
The Cost of Freedom
We pick it up
Nothing said
We pick it up
We watch the City fall down
We pick it up
Because of Freedom
We walk hand in hand
God Save America
We pick it up
We watch the City fall down
We pick it up
See the Capital Standing strong
Because of Freedom
We pick it up
We are American
We pick it up
Because of Freedom
We pick it up
Long live Freedom
We pick it up
Long live Freedom
We pick it up



An Attack Against America

Timothy Elliot

A day like no other that anyone can remember
An attack against America on the 11th day of September
Terrorism has hit us hard in our own homeland
An attack against America, and everything for which she stands
A plot to leave this country with a look of one massive grave
An attach against America, land of the free, home of the brave
Buildings were destroyed, thousands have died.
An attack against America, they destroyed our buildings, but not our pride
To recover from such devastation, who knows how long it may take
An attack against America, our hearts may be broken, but our spirit will never break
Now a more united America strands strong, proud and defiant
The only success they've accomplished is awakening an angry sleeping giant



*The Board and Staff
of the Self-Advocacy
Association wish you a
joyous Holiday Season
and a Happy and
Peaceful New
Year.*



Self-Advocacy Association, NYS
500 Balltown Road
Schenectady, New York 12304
518-382-1454
518-382-1594 fax
sanys@capital.net
www.sanys.org