

ADVOCACY 101

Individuals – either connected to an association, organization, company or simply engaged as a citizen advocate – can influence the public decision-making process that determines so much of our daily lives including what we pay in taxes, the type of health care we receive, our education, the jobs available to us, etc.

In order to maximize the effectiveness of your influence, it is important that you have an understanding of the processes at work in developing government policy and how you can work as part of a local, regional, statewide or national network to achieve public policy objectives.

WHAT IS ADVOCACY?

“Advocacy” is defined as “The act of pleading or arguing in favor of something, such as a cause, idea, or policy; active support.” (American Heritage Dictionary 2000)

How does Advocacy differ from the “L” word?

For a variety of reasons, “Lobbying” has been a practice viewed with some level of disdain by the public. It could be that most of the public does not recognize “Lobbying” for what it is: “To try to influence the thinking of legislators or other public officials for or against a specific cause”. Not that much different than advocacy, right?

In a more technical sense under the modern political system, lobbyists are also generally compensated for the services they provide and it is this factor that triggers compliance with various ethical and lobbying disclosure laws governing their activities. The effectiveness of these laws is presently a matter of great debate.

In addition, lobbying is a guaranteed RIGHT in America – “Congress shall make no law... abridging... the right of the people peaceably to assemble, and to petition the Government for a redress of grievances.” (1st Amendment, United States Constitution). So, in a sense, if you have ever spoken with a public official on an issue that you are for or against, then you have “lobbied” your official and “advocated” on behalf of a cause. However, you are usually not subject to ethical and lobbying disclosure laws unless you are compensated for your activities.

Generally, legislators and other elected officials are hardworking, dedicated individuals who take pride in being a public servant. It is important to be aware, however, that they often don’t have the specific information – or necessarily the same commitment as you do – on a particular topic or issue nor a complete understanding of how their decisions will affect the lives and welfare of various citizens. That’s why it is vital for you to be an active and effective advocate on behalf of your organization.

Another distinction between “advocacy” and “lobbying” is the line between “fall on your sword” activism and the ability to “make a deal” accomplishing part of your objective.

*Source: Capital Associates, Inc.
Updated October 2006*

THE ARC OF PENNSYLVANIA TAKE ACTION CHECKLIST

I. UNDERSTAND THE ISSUES

1. Check out The Arc of PA website www.thearcpa.org or call 1-800-692-7258 to find out the key issues
2. Sign up for The Arc Action Alerts- to be alerted when to take action on key issues(<http://capwiz.com/thearc/home/>)
3. Read The Arc of PA's Position Papers and Resolutions on key issues, accessed through www.thearcpa.org, click "Disability Resources", and then click :Position Papers and Resolutions"
4. Learn who to contact on specific issues- identified in Action Alerts

II. GET INVOLVED

1. Contact your local chapter of The Arc (go to The Arc of PA website www.thearcpa.org , click "Chapters" or call 1-800-692-7258- to find out your local chapter contact information.
2. Become a member of your local chapter of The Arc and/or ask to join the chapter's advocacy or government affairs committee.
3. Develop a relationship with your local and state elected official. Become a resource to them. Offer constructive feedback when asked. The ideal relationship is when the elected official contacts you to ask you questions about issues affecting citizens with disabilities.
4. Ask about, attend, or join committees, such as Local Right to Education Task Force, Parent Support Groups, the county MH/MR Board, Disability Councils, etc.
5. Attend SAGA Day (System Advocacy and Governmental Affairs) at The Arc of Pennsylvania, which is a free or low-cost training day in Harrisburg in April held to inform members of The Arc of the key issues
6. Attend trainings offered locally (IEP's, Transition, Advocacy Skills etc.)
7. Access support offered by your local chapter of The Arc (Early Intervention, Educational, and Person-Centered Advocacy or social and recreational opportunities)

III. TAKE ACTION (*not just in a crisis)

1. Action Alerts – through local chapter website or www.thearcpa.org
2. Emails to local and state elected officials
3. Letter writing to local and state elected officials; examples found in "[Advocacy Tools](#)" and "[Telling Your Story](#)"
4. Phone calls to local and state elected officials
5. Visit Legislators in Harrisburg or their district office- information on addresses and contact numbers at www.legis.state.pa.us
6. Attend community events and talk to legislators/officials
7. Inform others of key issues and encourage them to GET INVOLVED
8. Invite officials, both state and local to visit local programs offered by The Arc, or to its special events, to educate them on issues important to the chapter and/or involve them with constituents

IV. STAY INVOLVED

1. Services constantly change (EI, school age, Transition, Adult life) so it is important to stay informed and involved.
2. Provide feedback to your local or state chapter of The Arc regarding meetings with your elected local and state officials



2009 Public Policy Priorities of The Arc in Pennsylvania

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***SEE MOST CURRENT VERSION OF “THE ARC OF
PENNSYLVANIA LEGISLATIVE PRIORITIES” FOR
DETAILS***

SAMPLE LETTER ON BUDGET CONCERNS

The Honorable Members Name
 The Senate or House of Representatives
 Address
 Address
 Harrisburg, Pennsylvania 17120

Dear Senator or Representative Name,

My name is _____ and I am a (parent, grandparent, advocate, individual, etc.) that lives in the (District number). As a constituent served by you, I am concerned that the 2008-2009 Pennsylvania Budget does not make people with intellectual and developmental disabilities a priority. (If it is on another issues- please refer to the Bill number or specific concerns)

Some of my key concerns are (list those issues that you are most concerned about). (Tell personal stories about how funding issues or this bill will effect your family.) (List agencies that provide support and services to you and your family- including any support groups- as well as The Arc). Describe how an action on this issue in a positive or negative way will impact those services and supports to your family.

I would welcome the opportunity to meet with you or your staff to discuss these and other issues vital to the wellbeing of my family.

SAMPLE LETTER ON ADULT PROTECTIVE SERVICES

As the mother of Mary, a 16 year old with Down Syndrome, I am very concerned that Pennsylvania is one of only 6 states in the nation without a protective services system for vulnerable adults ages 18 to 59. Even though I hope Mary is able to live as independently as possible in the Erie community, I worry about her safety.

Similar to persons protected in our state's child protective services and older adult protective services, persons with mental retardation and other disabilities are vulnerable to abuse. The Legislative Budget and Finance Committee issued a report in 2003 calling for such a system.

As a member of The Arc of PA and an advocate for all vulnerable adults with disabilities, I support the creation of an adult protective services system for adults ages 18 to 59.

Senate Bill 1049, introduced by Senator Pat Vance, would create such a system.

I am asking you to contact Senate Leaders and the Senate Aging & Youth Committee and urge that they make passing SB 1049 a priority this year. Mary, our family, and other

families of individuals with developmental disabilities, in Erie and across the State, are counting on you!

Sincerely,

Your Name

Address

Town, Pa. Zip Code

E-mail Address- if you have one

HOW TO HAVE AN EFFECTIVE SITE VISIT FROM YOUR REPRESENTATIVE

Site visits provide important opportunities for grassroots advocacy. It is always beneficial to build a relationship with your representatives as early as possible and site visits are an excellent way to build this relationship. Your professionalism and courtesy to representatives will be remembered when you later need to ask them for assistance. Post-visit anecdotes help spread positive news of your organization's issues to other members of the legislature.

- Don't be worried if your representative is late for their visit. Delays may arise in busy schedules.
- Arrange for an opportunity for the representative to see how your organization functions.
- Provide advance notice and information to your organization members. If your representative is actively working on a local problem, educate your organization about that situation so they can ask or answer questions.
- Have photos of the representative taken with your organization's members and distribute them as appropriate (i.e. website, local media, etc.).
- Have organization members write about the visit and submit their pieces to your local newspaper. Include photos.
- Invite the local media to cover the event.
- Have the organization's members send thank you notes and enclose any information you promised to send.

EFFECTIVE ADVOCACY 101 – HELPFUL HINTS

- Be Authentic, Passionate and Professional. Maintain the right attitude about government and your role in it.
- Have a general understanding of how the executive and legislative branches work.
- Identify who represents you – get to know your elected officials and their staff.
- Meet with your legislators. Do your homework – review the legislators' background on their websites. Establish a personal connection by demonstrating genuine interest in learning more about him or her.
- Do not underestimate public officials. With few exceptions they are honest, intelligent, hard working people who want to do the right thing. Your job is to inform them of what you think is right.
- Know your issue. You don't have to be an expert, but be informed and be able to identify and convey the subject that concerns you. Do your homework and know the pros and cons of your position.
- Offer to the legislator yourself as an information resource on your issue.
- Present the facts in terms of where you work or live and demonstrate the impact of the issue on the officials' constituency. Be yourself and tell your story.
- Write the appropriate Representative, Senator, Committee Chairs, the Governor and executive departments. Respectfully request written replies.
- Work closely with legislative staff.
- Attend "town meetings" when your Representative or Senator is in your district.
- Schedule appointments with your legislators during their time in their district offices.
- Develop and share specific recommendations with your public officials.
- Consider media involvement where appropriate. Consider "letters to the editor," invite the media to your public affairs events, provide special interest feature stories that include real life situations that support your position, participate in radio and television call-in programs, and consider "advertising" your position.
- Offer to write a letter to the editor recognizing the good work your legislator has done.
- Write thank you notes to staff that have been helpful in arranging meetings or providing information.

EDUCATING MEMBERS ON ADVOCACY

Educating your members on advocacy is an important part of supporting your issue. Teaching them about advocacy will enable them to mentor others.

- **Hold a workshop.** Hold a 1-day workshop or a session during one of your annual conferences on advocacy. Invite members to learn about all the tools and resources that are available to them.
- **Print materials.** Print materials stating your current issues and how members can help. Include legislators' names, addresses and phone numbers and e-mail so that they can be contacted to discuss current issues. Include information on grassroots campaigns, public relations campaigns, etc.
- **Teach them about the political system.** Offer member information on the political system and how state government works.
- **Ask members to commit to be a grassroots contact.**

Educate your members to understand how legislative decisions are made and that these decisions are driven by a variety of factors. This will help the members continue to be engaged even when their legislator may or may not be able to support their issue. The deciding factors for a legislator include:

- **District factors.** Does the issue affect the district? Has the legislator heard from constituents?
- **Personal factors.** Is this issue important to the legislator? Has the legislator (or his family) been affected personally by the issue? Do specialized degrees or training (legal or medical, for example) affect his or her perception of the issue?
- **Policy factors.** What are the implications of the issue? What are the legislator's personal beliefs on the issue? Is there a fiscal impact?
- **Personal political factors.** Are there re-election concerns related to the issue? Do the legislator's political supporters—including campaign contributors—support the issue?
- **Party political factors.** Is this a priority issue for the legislator's party? Could the legislator's party run on the issue in the upcoming elections, or would the issue likely be used against the legislator's party?

HOW TO CONTACT AND MEET YOUR LEGISLATOR

Meeting with a legislator is an extremely important part of advocacy. It is an opportunity to gain a powerful supporter for your organization. Good planning and preparation will make for an effective meeting.

- **Develop an agenda.** Pick a few main issues to discuss and choose your talking points. Choose at least one issue that does not require an increase in funding.
- **Do your homework – on the issue, and on your legislator.**
 - **Issue:** Prepare a history of your issues and know all of the background information, as well as recent developments.
 - **Legislators:** Who are my representative and senators? What is their legislative record and general philosophy? What issues are they passionate about? What committees are they on? Are they newly elected, or more senior? What political party do they belong to?
- **Make an appointment.** Let the person scheduling the appointment know what you want to discuss and how much time you will need. Also inform them of everyone who will be attending the meeting
- **Be punctual.** Legislators keep very busy schedules. They generally don't have time to wait for people who are not on time.
- **Dress appropriately.** Your attire should be conservative and professional.
- **You may actually meet with a staffer or an aide.** If the legislator is unable to attend the meeting for some reason, you may meet with a member of their staff. It is important to treat them with respect as they are in a position to help your cause.
- **Introduce yourself.** State your name and your role within the realm of your organization.
- **State your objective.** Immediately state the issue or bill you wish to discuss.
- **Thank him or her for previous support.** Know how they have voted on your issue in the past and show appreciation.
- **State local concerns.** Explain how this issue effects your community and the surrounding region.
- **Refer to pending legislation.** State how supporting pending legislation will help your cause.
- **Use anecdotes.** Personal stories can help any legislator relate to the human side of an issue.
- **Encourage questions.** Educate the legislator as much as possible. If you don't have an answer for a question, say so and offer to find the answer and get back to them.
- **Ask for the legislators support.** Let the legislator know you want a firm response without threatening him or her.
- **Ask what you can do.** Offer to provide further information, arrange another meeting, etc.

- **State the facts.** Do not fabricate information, lie or exaggerate.
- **Be sure to include your name and address.** This way a response can be mailed to you.
- **Address your letter properly.**

PROPER FORMS OF ADDRESS

(STATE)

GOVERNOR:

The Honorable _____
Governor, Commonwealth of PA
Room 225, Main Capitol
Harrisburg, PA 17120
Dear Governor: _____

SENATORS:

The Honorable _____
The Senate of Pennsylvania
Senate Box 2030**
Main Capitol
Harrisburg, PA 17120-30**
Dear Senator _____

REPRESENTATIVES:

AGENCIES:

The Honorable _____
House of Representatives
House Box 202020
Harrisburg, PA 17120-2020
Dear Representative _____

CHAIRS OF COMMITTEES

The Honorable _____
Chair, The _____ Committee
The Senate of Pennsylvania
Senate Box 2030**
Harrisburg, PA 17120-30**

The Honorable _____
Chair, The _____ Committee
Pennsylvania House of Representatives
House Box 202020
Harrisburg, PA 17120-2020

SECRETARIES OF EXECUTIVE

The Honorable _____
Secretary of _____
Room _____/or/ P.O. Box _____
Harrisburg, PA 17120
Dear Secretary _____

**Add Senate District Numbers

(Note: any number under 10 should be written as 01, 02, 03, etc.)

(FEDERAL)

SENATOR:

The Honorable _____
United States Senate
Washington, DC 20510
Dear Senator _____

REPRESENTATIVE:

The Honorable _____
United State House of Representatives
Washington, DC 20515
Dear Representative _____

Anatomy of a Typical Legislative Meeting



Before the meeting

Arrive 10–15 minutes before your appointment to meet with your group. Review your talking points and message and review what each person will contribute to the meeting. Assign one person to begin the meeting and one person to end the meeting.



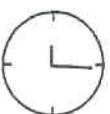
Introductions (5 minutes)

All the constituents should briefly introduce themselves at the start of the meeting. This is your chance to remind the legislator that you are constituents, but consider sharing a few unique details to underscore the fact that your group represents a broad cross section from the district.



Local stories and statistics (5 minutes)

Provide the legislator with local stories and/or some basic statistics from home. Lawmakers especially appreciate real-life examples that put a face on an issue. They also appreciate learning how federal money is spent in the district. (See sidebar that follows, "Five Conversations Your Legislators Want to Have," for more information.)



The request (5 minutes)

Stay on message! Make a clear request to the legislator or the staff. Ask for a commitment and then listen carefully to the response. Legislative offices will often need some time to consider supporting or opposing legislation, but they will often share important insights into their thought process. Remember to thank them before you leave.



After the meeting

Briefly meet with your group outside the office to compare impressions and to identify any follow-up work that needs to take place, such as sending requested information to the office. Remember to get business cards from any staff you meet with and send a thank-you letter soon after your visit. These notes help you form long-term, business-like relationships with these offices.

Source: Grassroots Games; Christopher Kush, MPP

EARLY INTERVENTION

NOAH ISN'T TALKING YET

I am the mother of Noah, who is now three years old. When Noah was about 12 months, I became concerned because he wasn't babbling or talking. He seemed happy and playful, but at times, he would get very fussy and frustrated when he would point to something and I didn't know what he wanted. When I asked our family doctor about this, he sent us for a hearing test to see if Noah was having trouble hearing. The hearing test came back normal. The doctor said not to worry and that Noah was "just a boy and boys usually start talking later than girls." I kept talking to Noah, saying words for him and telling him to "Say ____" But within a few months, Noah was still not babbling or using words, and now we both were frustrated! I was getting very worried that Noah would fall very far behind other children his age and not be ready for preschool. I called our local hospital asking about speech therapy. The hospital staff referred me to the local Early Intervention (EI) program.

I called the agency and they talked to me about my concerns, and scheduled an evaluation at my convenience, in my own home. She explained that all services were paid by the county and I would have no expenses. When the therapist and a coordinator arrived for the evaluation, they were very engaging with me and Noah. While one played with Noah, the other talked to me about our family history, family routines, Noah's strengths, etc. The evaluation session lasted almost 2 hours and they reviewed the results right then. Noah had a delay in communication and they recommended that he start speech therapy. When I asked where I need to take him for that, they offered several agencies that specialize in EI, and they come to the home. I was thrilled. Once I chose an agency, a second meeting was scheduled (also in my home), to develop a plan of treatment for Noah. I was so happy to be included in all the discussion and planning. We decided to have Noah begin weekly speech therapy sessions. His therapist came to our home weekly, for an hour each session. I participated in every session and the speech therapist explained the strategies ("tricks") she was using when playing with Noah. She helped me learn how to "read" to Noah, how to wait for Noah to get any sounds out, how I could imitate Noah, how I should talk to Noah, etc. By 18 months of age, Noah was beginning to use real words and I did not notice the fussiness and frustrations that he had prior to starting EI. As part of EI, the Coordinator, the speech therapist and I met every three months to review Noah's progress and discuss and any other concerns or needs. Over the course of his weekly therapy, the speech therapist and I would discuss new goals for Noah, to help him continue to improve. When Noah was 2 ½ years old, the speech therapist completed a re-evaluation. The results showed that Noah's communication skills were now normal. Noah was rapidly developing new vocabulary, putting words together in short sentences and talking like a chatterbox!! The Coordinator, speech therapist and I met for a final visit and they gave me specific contact information if additional concerns arise or if I had questions.

I cannot say enough about the benefits of Early Intervention, not only for Noah but for me as his mother. I learned how to follow Noah's "agenda" of development, vs. just what the books say. I believe that by starting speech therapy early on (age 16 months), we prevented future problems from developing. Today, Noah is no longer frustrated and I feel confident that he will be able to keep up as he starts preschool.

How We Were Able to Get a Transition Program in 1990

By John and Joe Angelo

When John was 18 years old and a senior in high school, his mother, Shirley, and I were very concerned because we knew that he was not ready for any kind of employment. He had an experience when he was 14 years old, working in a Salvation Army Day Camp, and that went pretty well, but that was not a part of his school program.

So, we talked it over with John, and he agreed to stay in school for three more years if we could get him some job training. Shirley, John and I decided, that it would be good if John could have some sort of a work-study program which was offered to seniors at our high school if they were not planning to attend college. They worked at a real job site for half of the day, and were in the class room for half of the day. We thought that would be good for John because he could gain real work experience, and at the same time continue to grow in his academic studies, and at least maintain the abilities he had attained in the his 13 years of formal education.

So, for his last IEP of his senior year at IAHS, I asked the Superintendent of the School District to attend. He told me he rarely went to IEP meetings, and would probably send one of his assistants. I said that would be fine, but I thought he would want to attend because it would be the first ever transition IEP of many that would follow when the Transition Bill passed at the time it was in draft form in the legislature. To my surprise, the Superintendent of the school district actually attended in person!

When we attended the meeting, I had a copy of the Special Education Regulations and a copy of the draft Transition Bill. We suggested that he should take part in the work-study program that was already available to a sizable part of the student body. We wanted him to have some inclusion in the classroom, and to have work experience at regular job sites. The only extra expense to the school district would be for the job coaches John would need, and even that would eventually be picked up by OVR and by the Supported Employment program at ICW.

The district was reluctant, but I kept pointing out that the Transition Bill had a very good chance of passing, and that we would do whatever we had to do to get John the experiences he needed for employment during his last three years in school. I never mentioned the words "due process" because I really didn't think it would come to that, but some folks in the room might have considered it to be a possibility.

I'm sure that the reason for the reluctance was stereotypical thinking about people with Down Syndrome. None had ever taken part in the work-study program before. But none of them were as well prepared for the program as John. John was born in 1972, the first year for special education in Pennsylvania.

We reached an agreement that John could participate in the work-study program for six weeks, and then we would evaluate our decision. When we met again after six weeks, the job coach complained that John wasn't staying on task, that he did not try to find things to do when he completed a task, and that he was easily distracted. We pointed out that we knew John lacked the job skills necessary for competitive employment, that we noticed some improvement in his attitude about his work, and that he would certainly make the effort to succeed, and we got another six weeks.

After the second trial period, the job coach said that the progress John had made was terrific, and he had no doubt that he could succeed in obtaining regular competitive employment if he continued to improve. John's experiences included work at a toy factory, a grocery store, a nursing home and at the County Court house in the Voters Registration office. He was successful in all of those experiences. He graduated in June, 1993, became employed at a pharmacy in December, 1993, and will complete 15 years with that company this coming December.

Fortunately, we were able to be active members of The Arc in our county and I took an active role in the work of The Arc of Pennsylvania. Because of The Arc I was always informed of government actions regarding the welfare of people with disabilities, and I knew of best practices that were occurring in education as well as in other services for our constituents. I was able to approach those providing services for John with knowledge and confidence as well as a strong conviction about what was best for him.

So, to The Arc, Thank You Very Much!!

EDUCATIONAL SERVICES AND SUPPORTS

My seven year old son, Evan is on the autism spectrum. He is enrolled in our neighborhood public school in the Autism Support Class. He participates in regular education for math. He has been attending this school for the past two years. Since his diagnosis, I've been told to keep things structured and as routine as possible for him. So, making the transition from part time school to every day was challenging last year. There were "behavioral" issues that were addressed and a TSS was put in place. He was becoming familiar with the expectations. Despite all this, Evan continued to exhibit difficulty transitioning. He did well for several weeks then total chaos. I didn't understand what was happening. Then, I remembered the key words----routine and structure. While at school, Evan flows with routine. I started to notice that whenever he had breaks/time off from school, he would return upset and it would take him time to readjust to the "other" routine. Even though I would create visuals to help him understand the holiday and summer breaks, he just had a hard time getting back to his routine. When returning to school, he would pace, not follow directions and make those sounds as though he didn't want to be bothered. He would withdrawal from the learning process. It would take another two weeks for him to re-settle into the routine. Clearly, this is a relapse. When the extended school (ESY) year was offered, I thought that a routine during the summer would help. It did until the time in between the end of the program and school starting in September. Another change in routine. I know life is all about change, but my son, along with others who desperately gasp for routine cannot readily adapt no matter how much advance notice and preparation is offered.

There has to be something better for my son; our children. I did homework. I read about the Individuals with Disabilities Education Act (IDEA) and the federal rules for the Extended School Year and learned how Pennsylvania interpreted the law, I was aghast! There is nothing in federal regulation that states an ESY can only be for three days per week from 9am to 1pm over 6 weeks during the summer. IDEA, 300.106 states that *federal regulation does not limit a public agency from ESY services to a child with a disability during times other than the summer, such as before and after regular school hours or during school vacations, if the IEP team determines that the child requires ESY services during those time periods in order to receive FAPE*". The federal government does not define "break" as summer vacation. A break is defined as an interruption in the educational program. Additionally, the Basic Education Circular (BEC) published by the PA DOE which are guidelines for school districts, states, "*while many ESY programs are held during the summer, children eligible for ESY services can require weekend or even virtually continuous programming....?*"

Clearly, Pennsylvania can do more for our children. How can Pennsylvania say that they are offering an appropriate education to our children when my son struggles to regain his sense of order after these extended breaks?

I am asking you to support the implementation of PA DOE's own guidelines regarding the Extended School Year. Pennsylvania is mandated to offer ESY; how they do it is up to the school districts. There needs to be consistency across our state.

1. Offer ESY during the holiday and spring breaks

2. Offer ESY during the summer the week after school ends until the week prior of the new school year for a full day.

Budgets are always an issue, but not at the expense of our children. Supporting implementation that expands the ESY and holding the DOE accountable for enforcement is the right thing to do for our children---all our children who are entitled to a free and appropriate public education. Thank you on behalf of all children attending Pennsylvania public schools who receive special education services. Let's do it right!

ADULT RESIDENTIAL LIVING

I am the sister of a 42 year old woman named Rhonda, who lives in a residential program, with 2 roommates, with whom she has lived for 10 years. She also attends an Adult Day program.

Rhonda is diagnosed with profound mental retardation and some minor health problems- including high blood pressure and she is slightly overweight. She was placed in an institution for the first 25 years of her life, but now lives a full community life, including social and recreational opportunities that she enjoys with her family and roommates.

Our challenges lie with the constant turn over of the staff, both in her home, staffed by a residential provider, and her day program. She has a difficult transition when staff at either program leaves, and is depressed when the programs are understaffed and she is not able to participate in her regular activities, such as an exercise program at the Fitness Center, pottery class, concerts on the River, and volunteering at a Retirement Center. Most of the staff are young and enthusiastic, but move onto other opportunities, as the pay scale leaves them unable to afford the basics, never mind colleges loans, etc. The turnover rate nationally is about 72% annually. Could any business exist with a similar turnover?

Unless a commitment is made by state and federal government to make direct care staffing a valued job opportunity, and the pay scale is commensurate with that value, this will become a crisis that may become health and life threatening to my sister, as well as thousands of other Pennsylvania citizens with disabilities, who need support. That is why I am asking you to support the 3% Cost of Living (COLA) legislation- as an amendment to this year's proposed Budget. It will afford providers the ability to increase staff salary, to keep even with inflation.

ADULT COMMUNITY LIVING

A local chapter of The Arc received a telephone call from the law enforcement officer at the Humane Society regarding a person with an intellectual disability who had been cited for cruelty to animals. This individual was living in an apartment that had dog and cat waste through the home. The individual was about to be hauled off to jail if she did not turn surrender the animals or if the home was not cleaned. The humane league did not want to prosecute this woman, however they did not believe she knew what was about to happen.

An advocate contacted the county's MH/MR and discovered that this individual had a closed record with the County. The advocate was able to discuss the situation with her former supports coordinator. The advocate then drove to the person's home. The person was not home although her sister and another person were there cleaning up the home. After explaining that she was there to help she spoke with the sister. The home, despite efforts by the sister, was still filthy. The individual living there is not able to keep up with having her own apartment independently. The Arc chapter has contacted MH/MR to have the case reopened and will assist with transportation. We were just notified that this person has not paid her rent and is now being evicted from her home. We will continue to work with her and MH/MR until she has a plan of support in place.

My name is Sara Wolff and I would like to share a little bit about myself with you. I definitely have something unique about me—and that is an extra-chromosome. You can't catch it, buy it, or even inherit it. It is something that happens in the 1st 24 hours of conception. There are 23 sets of chromosomes, in my case, the 21st takes on an extra-chromosome giving me 47 instead of 46, and a label that I have Down Syndrome. There are many characteristics associated with DS but none of them has ever stopped me from doing anything! (Except for the fact that my nose is too small and glasses they fall right down on me).

I don't think of myself as having "DOWN" syndrome but "Up" syndrome because I am an upbeat and positive person. I have been raised with the motto "Never" say "Never" and the words "I can't" don't exist.

"Inclusion" began the moment I was born. My family included me in everything they did. I saw all the activities my brothers and sister were involved in at church, school, and community. I knew that I wanted to do these things also. I was fortunate to have parents who believe in me. Thank God, they didn't listen to the words "Kids like these," "Can't," "Won't," "Don't," or the psychologist who said "She doesn't have the intelligence to walk through those doors alone." Instead, they met the challenge and listened to the words "You must become your child's biggest advocate, if you don't, no one else will." They saw "ability" not "disability."

Change is always difficult. Each school year began

with my mom meeting the teachers, hoping to ease their fears and help them greet the idea of inclusion with an open mind. She would tell them, "We don't expect miracles" just make her a part of the class, use your instincts and together we can create not only a challenging but a rewarding educational experience for everyone. Every September began with much doubt on their part, but by June they were believers.

Look around the room— unless you have a twin here we are all different – and yet, we all want a lot of the same things. Families that love us, friendships, good jobs and opportunities to be successful.

I was an included student from pre-school thru High School Graduation. With the help of a learning support teacher and the hard work of my parents I had a very successful educational experience. I am proud to say I even made the honor role several times. I learned from my classmates and they learned from me. I wasn't just a follower - sometimes I was the first to do new things like when we had to memorize the Presidents or recite the Preamble to the Constitution. (Please don't ask me to do that now).

I participated in extra-curricular activities and made lasting friendships. I was a cheerleader, played the drums in the Concert/Marching band. I went on yearly trips, including marching in the Disney World parade. I danced in our High School Variety Show for 4 years. I not only entertained the audience, but gained the

respect and admiration of my peers. They saw my "Ability" not my "Disability" and the standing ovations I received will be forever etched in my memory.

I loved Basketball, when I was younger I played on a team. My teammates and those on opposing teams learned to overlook differences and find similarities.

When it became too competitive for me to play physically I wasn't about to give up my love for the game. I became the Girl's team manager. I was able to feel the joy of victory and the disappointment of defeat.

A bond was built with my teammate's that has lasted longer than any season. I still hear from some of them and we talk about the good times we had.

My list of accomplishments can go on but the one that I am most proud of was organizing the 1st Buddy Walk in our area as my senior graduation project. My goal was to change hearts and attitudes towards people with Down Syndrome. The Buddy Walk is now an annual event. I do believe I have made a difference to promote awareness and understanding of the potential of individuals with Down Syndrome.

But, life does go on, leaving high school to adulthood can be a tough road to travel, but that doesn't mean it has to be a bad one. Yes, it was hard to see my high school friends go off to college, something I would love to do, but I wasn't about to sit back and feel sorry for myself. I was determined to continue to be

an involved, inclusive member of society.

I have a job in a law office - which I enjoy. I take college courses and have earned 12 credits. I lecture at my church and a volunteer in my community. I am on the NEPA Arc board and recently I was appointed to the Pa. State Arc board. Last September I was appointed to the National Down Syndrome Society Board in New York as a self-advocate.

In March I attended the National Disability Conference in Washington D.C. I went to the Capital and met our legislative representatives from Pa hoping they will pass the bills for people with disabilities to insure they have a better life. I hope to continue to speak as an advocate for myself and for others.

I have painted a rosy picture for you, but it hasn't always been easy. There was a time when I wanted to change my face, but I don't feel that way anymore. This face is who I am. This face has made a difference in people's lives. It doesn't matter what we look like on the outside but it's what's inside that counts. I believe in my uniqueness and I am proud of who I am.

Recently, it was mentioned to one of my high school guidance counselors, "How lucky I was to have a school like North Pocono accept me. His reply, "We were the lucky ones to have Sara in our school." When I heard this, a tear came to my eye and joy filled my heart, knowing I have open doors and made a difference.

CLOSURE OF INSTITUTIONS

My Life – My Story

Jean S.

I was born in 1962. The second of eight children born to parents who were both heavy smokers and alcoholics. I was diagnosed with mild retardation. I attended special education classes in Philadelphia and was placed in an institution. Living in an institution was like living in a prison. Staff abused people by smacking us, cursing at us, calling us names and sometimes threw us up against a wall. People with disabilities do not belong in institutions. I want to see them closed.

I am writing this story because I would like to see all my brothers and sisters out of the institution and in the community where they belong.

I moved into a Community Living Arrangement. I lived there for 13 years.

I also lived with a family, which was nice but they did not celebrate holidays. I am living in my own apartment for the last 4 years and I again celebrate holidays.

I worked in a sheltered workshop. I usually did assembly work on occasions I worked in the office-answering phone. After expressing interest in competitive employment and working with a job coach, I became empowered and was employed by Public Interest Law Center of Philadelphia. I worked there for 3 years before landing my present job with the Disabilities Law Project where I have worked as an Administrative Assistant for 15 years.

I have been lucky to have a lot of friends and family who always look out for me and trust me in working in my personal life. It took many years and a lot of work by me and advocates who worked with me, but I now live alone and work in competitive employment. I am working at a job where I can make a difference to people with disabilities. I am a Board Member of Liberty Resources, Vision for Equality, Developmental Disabilities Council and The Arc of Pennsylvania. I serve on The Arc's Advocacy Capacity Committee where we discuss ways to teach other people how to advocate for themselves within their community and with their legislators.

I am very passionate about what I do and help others to live a life like mine. I love to just hang out with family and friends.

FIVE CONVERSATIONS A LEGISLATORS WANTS TO HAVE WITH YOU

1. What the local statistics are

State legislators have access to an extraordinary amount of information but much of it is aggregate national or statewide data. Local constituents can present data directly from the district, a welcome and essential component of decision-making.

2. How state monies are being spent in the district

State legislators are interested in how state programs actually benefit their constituents, especially if it can be demonstrated that the money is wisely managed.

3. Real life stories that illuminate the statistics

Statistics are somewhat meaningless unless they can be understood in a real-life context. Personal stories help legislators understand your issues and help make your position accessible and compelling. Stories are also easily used in floor speeches and media sound bites.

4. How your organization accesses voters in the district

Local organizations often publish newsletters and regularly host community events. Using these vehicles to discuss pending legislation can present lawmakers with a welcome opportunity for visibility.

5. What specific legislative action would make you happy

Legislators never like to say “no” to constituents, especially those who are working hard to improve life in the home district. Make a clear request for action.

Source: Grassroots Games; Christopher Kush, MPP

Typical Chronology of Activities During the 23-Month Pennsylvania Legislative Cycle

January: Legislative Cycle begins

February (Tuesday of first full week): Governor presents Budget Address to joint session of the General Assembly

Late February – early or mid-March: Senate and House Appropriations Committees budget hearings regarding the Governor's Proposal

June 30th: End of current Fiscal Year; Deadline for budget agreement for next Fiscal Year

July 1st: Beginning of annual Fiscal Year

July and August: Typically summer recess for the General Assembly although legislative committees often use the time for public hearings, etc.

September – December: Fall legislative session

December – mid-January: Recess between legislative sessions

Mid-January: Beginning of spring legislative session

February (Tuesday of first full week): Governor presents Budget Address to joint session of the General Assembly

Late February – early or mid-March: Senate and House Appropriations Committees budget hearings regarding the Governor's Proposal

April or May of election year: General Primary election

June 30th: End of current Fiscal Year; Deadline for budget agreement for next Fiscal Year

July 1st: Beginning of annual Fiscal Year

July and August: Summer recess; legislators are campaigning in the district for the November elections

November (Tuesday of first full week): General Election

Up to November 30, 2006 – “Sine Die” Session – Defined as “without assigning a day for a further meeting or hearing; a final adjournment.” Also called “Lame Duck” Session. Legislative session ends on or before Nov. 30th

*Source: Capital Associates, Inc.
Updated October 2006*

Standing Committees of the PA General Assembly

Senate

Aging & Youth
Agriculture & Rural Affairs
Appropriations
Banking & Insurance
Communications & Technology
Community & Economic Development
Consumer Protection & Professional Licensure
Education
Environmental Resources & Energy
Ethics and Official Conduct
Finance
Game & Fisheries
Judiciary
Labor & Industry
Law & Justice
Local Government
Public Health & Welfare
Rules & Executive Nominations
State Government
Transportation
Urban Affairs & Housing
Veterans Affairs & Emergency Preparedness

House of Representatives

Aging and Older Adult Services	Insurance
Agriculture and Rural Affairs	Intergovernmental Affairs
Appropriations	Judiciary
Children and Youth	Labor Relations
Commerce	Liquor Control
Committee on Committees	Local Government
Consumer Affairs	Professional Licensure
Education	Rules
Environmental Resources and Energy	State Government
Ethics	Tourism and Recreational Development
Finance	Transportation
Game and Fisheries	Urban Affairs
Health and Human Services	Veterans Affairs and Emergency Preparedness

Helpful Internet Resources for Pennsylvania Advocates

Pennsylvania Executive Branch

Governor's Office	http://www.governor.state.pa.us/
Attorney General	http://www.attorneygeneral.gov/
Auditor General	http://www.auditorgen.state.pa.us/
State Treasurer	http://www.patreasury.org/
Commonwealth of PA	http://www.state.pa.us/

Pennsylvania Legislative Branch

The PA General Assembly	http://www.legis.state.pa.us/
PA State Senate Website	http://www.pasen.gov/index.cfm
PA Senate Democratic Caucus	http://www.pasenate.com/
PA Senate Republican Caucus	http://www.pasenategop.com/
PA House of Representatives	http://www.house.state.pa.us/index.cfm
PA House Democratic Caucus	http://www.pahouse.com/
PA House Republican Caucus	http://www.pahousegop.com/
Session Information	http://www.legis.state.pa.us/cfdocs/legis/home/session.cfm?papowerNav=%7C

United States Government

The White House	http://www.whitehouse.gov/
US Senate	http://www.senate.gov/
US House of Representatives	http://www.house.gov/
The Library of Congress	http://www.loc.gov/

Miscellaneous

PA Department of State	http://www.dos.state.pa.us/DOS/site/default.asp
PA Democratic State Committee	http://www.padems.com/index1024.html
PA Republican State Committee	http://www.pagop.org/
Campaign Finance	http://www.campaignfinance.state.pa.us/
Pennsylvania Code Online	http://www.pacode.com/
Pennsylvania Bulletin Online	http://www.pabulletin.com/
PA Manual	http://www.dqs.state.pa.us/pamannual/site/default.asp
IRRC	http://www.irrc.state.pa.us/
Governor's Office of the Budget	http://www.budget.state.pa.us/budget/cwp/view.asp?a=3&q=167632
The Budget Process in PA	http://www.budget.state.pa.us/budget/llb/budget/budgetprocess/index.htm
PA Politics:	http://www.politicspa.com/
Making Law in Pennsylvania	http://www.legis.state.pa.us/WU01/VC/visitor_info/making_law/intro.htm