



News & Notes
The Arc of Pennsylvania
August 25, 2010

- 1. BUDGET & FMAP:** Congress finally passed legislation that would extend the state aid funding for 6 months (through June 30, 2011). The vehicle to get the aid to the states is via an enhanced FMAP rate (Federal Medical Assistance Percentage). (In Medicaid, the federal government matches state funding, essentially sharing the financial burden of Medicaid – by temporarily enhancing how much of that burden the feds absorb, the states can then redirect an equal amount from their share to fill other state budget holes). The FMAP passed by Congress was not the entire amount expected by the states, and therefore PA still has approx. \$282 million in either spending cuts or tax increases to cover for the existing Fiscal Year 2010-11 budget. ODP has said that the Governor and legislature have not come to agreement yet on how to fill the remaining hole, and thus ODP programs may be on the block yet again.
- 2. BOARD & PCE:** PCE will meet Sept. 10 in Harrisburg from 9:30 to 3 – contact PCE President Diane Carey with questions; The Arc of PA board will meet in Harrisburg Sept. 11 from 10:30 to 12:30. Contact President Paul Conway or Steve with questions.
- 3. NCE:** Steve attended National Conference of Executives of The Arc “summer institute” from July 29 through Aug.1; several good sessions held. The final session on Sunday was a session whereby a draft new logo and tagline were unveiled to attendees for The Arc. They promised it was not the final decision. A webinar is being held on September 7 at 2:30pm for interested Arc folks to hear where they are and next steps, and to give input. If you are going to have input on the logo and tagline, then you are strongly encouraged to provide it BEFORE they make a final decision. If you want to participate on the webinar, you must register for it. Go to www.thearc.org and log in to the “for chapters” link to get info. on how to register.
- 4. FEDERAL 501C3 STATUS:** All chapters should have, or be in pursuit of, their own federal tax exempt certification so they no longer rely on The Arc of PA’s group exemption. Please let Gwen know as soon as your chapter’s 501c3 exemption is approved by the IRS and you receive your designation letter. We are required to immediately remove any organization from our group exemption if they hold their own.
- 5. INCLUDE ME:** Include Me Consultants began meeting with parents and staff in selected school districts in July. The Bureau of Special Education is going to send a mailing to an additional 200 parents of kindergarten students in selected districts since the July mailing only yielded 26 responses statewide. Final student/district teams will be identified by 9/13/10. The Include Me website is not live but can be viewed at <http://sub.includemepa.org>. The Arc of PA issued a Request For Proposal, and received four proposals in response to it, for independent evaluation services for the project. A proposal review committee will be convened to review and score the proposals with the target date of 9/13/10 for proposal selection. A mentor training schedule for the Supplementary Aids and Services toolkit (SaS) is being developed and coordinated with PaTTAN’s Inclusive Practices Lead for selected districts. On Aug.19,

Steve met with BSE Director John Tommasini to review progress on the Include Me project and discuss challenges.

6. AFFILIATION CERTIFICATES: The Arc of PA is sending updated affiliation certificates to local chapters. Please look for them in the mail. We request you display them proudly at your chapter.

7. EDUCATION LAW CENTER: On August 9, Steve met with Ed. Law Center director Len Reiser and Policy Director Baruch Kintisch to discuss possible areas of future collaboration between their org. and The Arc of PA.

8. CHAPTER USE OF THE “R” WORD: Pursuant to Board resolution, 10 chapters are being sent letters asking them to immediately update their official chapter name with the PA Dept. of State Bureau of Corporations and/or their “mission” language on their 990 forms to eliminate use of the words “retarded” or “retardation”.

9. MH/MR COALITION: Steve attended meeting between CMS and the Coalition Aug. 13 in Philadelphia – the purpose of the meeting was to go over several issues with CMS expressing the Coalition’s concerns with how DPW is handling payment and other matters as it relates to the waiver agreement PA has with the feds – a follow-up meeting was agreed to by CMS and is tentatively scheduled for Sept 24. Also, Maureen attended coalition meeting Aug 17 during which the coalition developed a letter to the Governor urging that services to people with mental illness, intellectual disabilities, and substance abuse disorders not be cut as a result of the reduction in the FMAP funding anticipated in the FY2011 budget. Steve also participated on a Coalition workgroup on rates conf. call Aug.24 to discuss status and next steps for the coalition.

10. BOARD GOVERNANCE CHECKLIST: Every chapter president will receive a letter either thanking them for reviewing and signing, or reminding them to review and sign, the board governance checklist for FY 2010-11. Reviewing and signing this checklist annually is part of the affiliation agreement. It is intended to promote good board governance, as well as dialogue amongst board members and between board members and staff about their governance responsibilities.

11. CHAPTER 14 TRAININGS: Debbie Leggens with The Arc of Westmoreland County/Achieva assisted Pam to include the SAS information in a people friendly format to the “What’s New in Special Education” training. Pam did a training hosted by Vision For Equality in Philadelphia Aug 19 attended by about 30 people- and was simultaneously translated into Spanish for 7 participants. Upcoming trainings are in October. For more information, please contact Pam at pklipa@thearcpcpa.org

12. ADULT PROTECTIVE SERVICES: (SB699) Maureen attended a meeting July 29 to discuss strategy. Coalition members are arranging meetings with House leadership in their home offices to ask that the bill be moved quickly and without amendment. Maureen is working with chapters that have members in leadership position to facilitate meetings in their district.

13. SAGA: Pam and Maureen staffed the committee meeting Aug 17. Updates were given by each subcommittee. A questionnaire to candidates for Governor and US Senate was approved which The Arc of PA sent to the candidates Aug 18 with expectation of printing answers in the Oct. newsletter.

14. FINANCE & AUDIT: Steve met with The Arc of PA’s investment advisory, Orlando Maldonado, Aug.25 for their quarterly meeting – nothing out of the ordinary. Also, The Arc of PA’s annual audit (for FY09-10) is underway – auditors were in the office Aug11-12 – all seems to be going well.

15. MR TERMINOLOGY: Maureen met with Martin Indars, Legislative Director for Sen. Andrew Dinniman (D-Chester) to discuss SB1443 which amends the MHMR Act of 1966 by replacing “mental retardation” with “intellectual disability.” The Arc of Chester County’s Diane Carey attended the Senator’s press event unveiling the bill. On the federal level, “Rosa’s Law” (the bill dealing with the issue in federal health, education and labor policy statutes) unanimously passed the US Senate Aug 5. An identical bill now needs to pass the House in Sept.

16. SPECIAL EDUCATION HB 704: Advocacy efforts continued in recent weeks to get a commitment to move the bill to the Senate Floor, before the end of the fall session. An important date is September 21st- when we are asking advocates to attend the Senate Education Committee hearing in Harrisburg, when Representative Strula presents HB 704 to this Committee for its consideration. A strong showing in the audience during this Committee hearing will symbolize support in the community.

17. WAITING LIST: Steve did conf. calls with PA Waiting List Campaign July 28 and Aug.18; discussed were the campaign’s “flash freeze” demonstration, updates on budget impact on WL initiative, and concerns about rate policies by ODP and their impact on people with significant needs, as well as preparing for the PAWL’s meeting with Kevin Casey Aug.26.

18. RIGHT TO EDUCATION RETREAT: Walmart State Giving Program awarded The Arc of PA a \$10,000 grant to support an effort to strengthen its training program – a portion of the grant was used to put on a retreat for Local Task Force chairs/co-chairs held in State College Aug7. 29 LTF members, representing 17 LTF’s attended. The day long retreat consisted of workgroup sessions that addressed the challenges of parent participation, IU supports, meeting management and responsibilities of chairs/co-chairs. Ken, Pam, Todd facilitated the retreat, along with support from PDE chair, Amy DeLuca.

19. COMMUNITY PROVIDER RATE WORKGROUP: Steve attended a meeting of the rate workgroup July 27; Steve missed meetings on July 29 and Aug.5.

20. PSEA PANEL: Pam participated on a panel during the PA State Educators Association Leadership Conference July 28 at Gettysburg College. She presented information to the teachers of regular education, as well as special educators, on The Arc of PA, its local chapters and our priority issues in the educational area. Additional panel members were from DRN and Parent Education Network.

21. DAY OF SHARING: Steve attended a “day of sharing” at White Haven Center Aug17; Sara Wolfe and Pam Zotynia (The Arc of PA board members), and Don Broderick and Pat Quinn from The Arc of NEPA, were also present. Ilene Shane from DRN and a few of her staff were also there. The event was intended to bring together advocates, center staff, parent group reps, and union reps to meet each other and discuss service/system issues. Sara, Don, Pat and I did a short tour of a portion of the facility afterward.

22. PATTAN WORKGROUP: Pam was invited to participate in a workgroup to include LRE questions on Cyclical Compliance Monitoring Forms- adapted from the LRE forms used in the Gaskins Settlement. This is a follow- up to the workgroup that helped to develop those forms. They will continue to meet in an effort to include these questions on the forms - and evaluate the results during spring 2011

23. STATE CHAPTER PUBLIC POLICY STAFF: Pam and Maureen participated in the monthly call facilitated by The Arc of US for state chapter policy staff - to discuss issues that are of common concern to all state chapters of The Arc. This month’s call was focused on the Health Care Reform and how chapters

can best present information to its members and families. Discussion was on fact sheets, webinars and links to explain the complex issue.

24. EMPLOYMENT STUDY GROUP: Maureen staffed a meeting of the full study group at The Arc of PA's office Aug 18 to discuss next steps. The group will be preparing a report to present to the SAGA committee Nov 30 in preparation for the Jan Board meeting.

25. EMPLOYMENT: Maureen met with Diane Cashman of ODP to discuss the MIG (Medicaid Infrastructure Grant which is to fund activities to promote employment of people with disabilities and promote cross system collaboration) that was submitted July 22, and how The Arc of PA can offer input. Maureen worked on a SPT (Stakeholder Planning Team) transition document for the next administration which has been submitted to the SPT committee for review.

26. CHAPTER RELATIONS: Jeanne Downey chaired and Steve staffed conf. call meeting of the committee; discussed with updates on a few chapters it is believed are struggling; chapter dues delinquencies were reviewed; a workgroup was formed to develop a survey that will be used to enable local chapters to assess the state chapter; and, an status report was provided on chapters securing their own 501c3 exemption letters from the IRS.

27. PREDETERMINATION FOR DEATH PENALTY: A hearing on SB628 was held by the House Judiciary Committee Aug 16. The Arc of PA facilitated the attendance of Professor Jim Ellis of The University of New Mexico (who argued the Atkins case before the US Supreme Court) to provide testimony in support of SB628. The Arc of PA's board member, Bill Burke, provided testimony on behalf of The Arc of PA. SB628 has passed the Senate overwhelmingly and is now before the House Judiciary Committee. Senator Mary Jo White has championed the issue and attended the House hearing, co-chairing the committee hearing along with Chairman Caltagirone. Steve and Maureen participated on a coalition conf. call Aug 23 to discuss strategies to move the bill out of committee. Maureen will be working with Coalition members to contact committee members. Sen. White has asked Rep. Caltagirone to schedule a vote when session returns – the vote is tentatively scheduled for Sept. 15.

28. PERSONAL CARE HOMES: Maureen joined a PCH Reform Coalition meeting July 27 with DPW Secretary Dichter to discuss concerns with the draft policy on Certificates of Occupancy and fire safety.

29. PENNHURST PROPERTY: Steve staffed a conf. call of the Executive Committee Aug.23 to discuss a proposed "haunted attraction" at the Pennhurst property. The Arc of Chester County has contacted township officials requesting they put a stop the thing – local state and federal officials have also been contacted and some appear interested in helping stop the enterprise. Advocates' complain such a thing reinforces negative stereotypes of people with intellectual disabilities and desecrates the memories of those forced to live at Pennhurst in isolation from society. The committee agreed to support the local chapter efforts and will consider getting more involved at the Sept. 11 board meeting.

30. DUAL DIAGNOSIS: Maureen joined a webinar July 28 to learn about the Peer Specialist program, the MOU (memorandum of understanding) between OVR and OMHSAS, and how training is handled for the program. Maureen also met with Dina McFalls, Director, Philadelphia Coordinated Health Care, and Lynn Patrone-Ruppel, Behavioral Health Connections Aug 20 to discuss ways The Arc of PA can support their efforts in this area.

31. PENNSYLVANIA RESOURCES: "The Partnership" has updated the publication "Understanding the PA Mental Retardation System" also known as the *Green Book*. The new version is titled

“Understanding the Office of Developmental Programs in Pennsylvania: Mental Retardation and Autism Services” aka the *Gold Book*. This publication provides an introduction to the Mental Retardation system, describing how the system works and is funded. There are chapters that will help individuals understand details about the system, including how to register, the waivers, different service models and what to do if you have a problem. There are two new chapters, one on Autism Services and another on transition from school to adult life. Also included in the attached publication are commonly needed forms, resources, contact information, a listing of advocacy organizations and a glossary. It can be downloaded at <http://www.temple.edu/thetrainingpartnership/resources/#goldbook>.

32. MEET AND GREET: Maureen met with Rich Long, Executive Director of the PA District Attorneys Association Aug 24 as a disability awareness outreach.

33. UPCOMING: Steve attends PAWL mtg. with Kevin Casey Aug.26; Maureen joins BAF call re: Autism study Aug 26, Maureen joins PA SILC HCBS call on Aug 26, Pam does HB704 conf. call Aug30; Maureen attends APS meeting with DPW Sept 1; Pam meets with Senate Education Committee staff Sept.1; Steve does state Arc execs conf. call Sept.7; Steve does national rebranding seminar Sept.7; Steve attends PCE meeting Sept. 10; all staff attend board meeting Sept. 11; Steve and Maureen do MHMR Coalition meeting Sept13; Maureen attends MFP meeting Sep 13, Pam staffs SAGA Subcommittee on Ed/E.C. Sept.13; Maureen joins Aging/MR County Team Webinar Sept 15; Maureen attends SPT meeting Sept 16; Maureen presents employment testimony at PA State Advisory Committee of the Commission on Civil Rights Sep 16; Steve does Temple University’s Institute on Disabilities community advisory committee Sept. 16.