



# *Commonwealth of PENNSYLVANIA*



*What are Some of the Self-Advocacy Organizations that Currently Exist in Your State? What are Their Major Activities or Functions?*

- ❖ Autistic Self Advocacy Network (ASAN)
  - ❖ Support groups (York, Butler), policy , advocacy, training (eastern PA)
- ❖ Pennsylvania Youth Leadership Network (PYLN)
- ❖ Self Advocates United As One (SAU1)
  - ❖ Help self-advocates have a voice in their community (training (DDC), ODP); leadership development, teleconferences
- ❖ Speaking for Ourselves (SFO)
  - ❖ Leadership development, outreach, information and referral, advocacy at ISP meetings, public policy (East, Central and West)
- ❖ Youth Outreach Union
  - ❖ Connecting youth with advocacy opportunities – want to do more w/youth with DD

## Answer the question:

*What are the resources for the self-advocacy organizations?*

<b>Name of self- advocacy organization</b>	<b>Who provides the resource(s)?</b>	<b>What resource(s) is provided?</b>
SAUI	DDC, ODP, DASH	Financial, Supported Leadership through Temple/ODP, organizing support through VFE
SFO	County MH/MR (Phila., Mont, Chester), DRN, ODP	Financial, Supported Leadership Temple ODP
ASAN	No financial resources at state level; grants to national association	Self-Supporting
Youth Outreach Union	Statewide family network as fiduciary	Youth support and advocacy support
PYLN		

*What has Worked in Your State for Self-Advocacy Organizations?*

- Speaking up and letting people know what we have to say – making a difference
- Self-advocacy organizations are represented on important committees and boards
- Support from government agencies, Developmental Disabilities Council
- Providing support through a state contract
- Organizations are successfully run by self-advocates

*What has Worked in Your State for Self-Advocacy Organizations?*

- Recognized as legitimate by state agencies and advocacy structures
- Supports are necessary to make groups as effective as possible
- Some self-advocacy organizations work together to coordinate efforts on particular issues
- Use of technology – for some
- Self advocates support, teach and learn from each other

*What are Some Challenges or Struggles That Your State Self-Advocacy Organizations Have Faced?*

- Funding to support efforts
- Size of state – difficult to have statewide mission and reach
- Transportation – difficult for people to get to meetings
- Support to attend meetings (PAS, etc.)
- Motivation to participate in a volunteer effort (people are having enough trouble organizing life – housing, employment, education) and sustain the effort

*What are Some Challenges or Struggles That Your State Self-Advocacy Organizations Have Faced?*

- Use of technology – not all people have access
- Understanding communication (different languages and ways to communicate)
- Service systems (mainly government) are inaccessible for many people
- Technology should be more available
- Service systems (mainly government) use outdated technology standards to block access

*What are you Most Proud of With Regard to Self-Advocacy Currently in Your State?*

- We can do it! People have passion and the work gets done! We make a difference
- Self-advocates have come a long way
- Some self-advocates are directing their own services and budgets
- Self-advocates are passionate and are creating system change



*What are you Most Proud of With Regard to Self-Advocacy Currently in Your State?*

- Number of self-advocacy groups across the state
- Strong leadership within the self-advocacy groups across PA
- Building of young leaders
- We get it done and we do it right!

## What Goals or Dreams Does Your State Have for Self-Advocacy?

- More communication, collaboration and cooperation among self-advocacy groups in PA
  - Community of practice on the web to bring people together
- Some unification to be sure everyone in the state is touched – pool resources
- People in the system will create more opportunities for self-advocates to contribute and make a difference

## Pennsylvania Team

- Oscar Drummond – Self Advocates United as One (SAU1) – Co-Team Leader
- Celia S. Feinstein – Institute on Disabilities/UCEDD, Temple University – Co-Team Leader
- Scott Robertson – Autistic Self Advocacy Network
- Savannah Logsdon-Breakstone – National Youth Leadership Network
- Debbie Robinson – Speaking for Ourselves
- Carolyn Morgan – Self Advocates United as One
- Chris Mielo – Pennsylvania Youth Leadership Network
- TBN – Office of Developmental Programs
- Graham Mulholland – PA Developmental Disabilities Council
- Mark Murphy – Disability Rights network of PA
- Kathy Miller – Institute on Disabilities/UCEDD, Temple University
- Sheila Hunter – PA Developmental Disabilities Council