

Supporting Families Community of Practice

July 11, 2016 Meeting

Four years ago, we convened the Supporting Families Community of Practice (CoP) in DC. As we look forward to our next year together, we took some time to reflect on what we've done together and what we hope to see and do in the coming years. CoP participants were asked five questions and the answers are captured in these notes.

What is one thing you've learned about supporting families?

- New members continuously joining
- I get much more info about the things that I don't know but was necessary for me and my daughter. The info which we can't find it anywhere.
- Connections with other stakeholders, parents, providers, and advocates. Face Time.
- Person centered thinking (this was the first place I did a deep dive into that philosophy)
- The families that have experiences about what you struggling with, they are able to help you better understand the issue at hand based on their experience. Support and help from the organization.
- Helping them make good decisions
- Attendance and participation has been high and consistent
- Relieve stress
- The most effective advocate is a self-advocate. The experiences someone needs can best be explained or articulated by the individual requiring the support.
- Gotten closer, greedy, selfish, distance, indifference, flake, come together, needed
- Supporting families are informative and eager to help and with communication
- Exposing people with new ways of doing things (tools)
- No communication
- Supporting families can be an overwhelming task without the cooperation of all agencies
- Supporting families is made better by personal face to face networking
- Training opportunities for agencies, advocates, self-advocates, especially in the area of person centered thinking and planning
- Everyone's family can be touched by disability
- Important to be a part of a community
- Help is available

- Evolved into a diverse discussion
- Someone has information that you can use in obtaining help and assistance in getting instruments or devices to help assist special needs
- There is no one right way. Need to get the word out about available supports. Issues change depending on stages of life.
- We all have a voice and it should be heard.
- Advocacy is important
- Who to talk about helping a family member get better help
- Advocacy I needed to build our community
- We help one another and support one another
- Positive profile trajectory for life
- Not only make them aware of resources, but also connect them to those resources
- Compartir informacion de los recursos locales disponibles para las familias
- Conocer como pedir ayuda para tener Buena orientacion familiar
- There is help for families – help, connect, love, and learn from each other
- We all have special family members that we want to advocate for
- Support needs to reach families where they are (different forms, modes of access, times of day)
- Agencies that are there to support people with disabilities by supporting that family they are directly serving that person keeping family afloat is essential to well serve the person with a disability

For new and longer term participants of the CoP, what is a question you have about this group of about how to best support families?

- How can you get better transportation?
- How the organization can help me get a job?
- How can this organization help me overall in training or a job setting?
- As a long term participant of the CoP, a question I have is how to raise more awareness for disability rights, awareness, support, or how to involve others more?
- Parent to Parent organization
- What formalized advocacy efforts are available to families and how can family members participate to advocate on important issues?
- How can we get young people to understand the value of advocating for their children?

- What can the CoP do to bring more provider stakeholders such as St. Coletta of Greater Washington, other DC Public Schools, Public Charter Schools, private schools, and adult education providers to the table?
- How can we get stats on the number of people employed by type of disability?
- Can we send information out to schools and clinics?
- Over the three years of CoP, do families feel they have more tools?
- Networking, doctors, schools
- I love this group, it is very, very helpful connecting with families and getting as much as information that I should get.
- How can families and supporters help the new participant to become a long term participant?
- Como puedo hacer para participar mas activamente en el grupo de apoyo familiar? (Translation: How can I participate more actively in the supporting families group?)
- Comunicación completa con las familias de todo evento que se va a realizar. (Translation: Complete communication with families about all of the events that are going to happen.)

What is one thing you can do to support the CoP and individual participants?

- LOVE
- Collaborate
- Make myself more available i.e. interest in advocacy groups, listening to other participants, offering “myself” to assist someone once.
- Advocate for inclusion at churches
- I can offer the CoP and individual participants the insight of my family’s and the families I have supported experiences and insight into their needs from this system.
- Write letters to the Mayor and Congressmen of the needs of people with disabilities
- Contribute: Let them know about the Protection & Advocacy Program in D.C.
- My experience as a parent of children with different issues: deafness, emotional health improvements
- I need the group to be very strong and helpful for each other and caring
- Show up
- Be in attendance – attend meetings
- What I can do: Bring my voice especially through my blog, to put important issues in front of D.C. government about citizens with developmental disabilities.

If you’ve been involved in this Supporting Families Community of Practice for a while, what is one thing you’ve accomplished because of the CoP?

- Share the information you have so that other can become familiar with the knowledge to help themselves and others.
- I've gained a clearer perspective of services and the fact that a lot of the supports overlap which sometimes is a waste of resource.
- Advocate
- How to write a positive description of my child so that people can get to know him better.
- Family workshops
- Got good information, met a friend, help me with the information I receive here.
- Thru CoP spreading the word, making level 1 systems change and harder for government to cover up the way they "provide" services (or don't).
- Getting rid of my fears of telling my story.
- Because I was here, I learned to see my daughter as more than her disability by using the one pager.
- I've come to understand there's a large group of advocate (self, family) in this city
- Because of attending the CoP I have gain the knowledge to advocate better for myself and others.
- SFCoP has been vocal to put PCT as a goal.
- Meeting other stakeholders in the disability community. I do trainings on human rights at DDA providers.
- I had more direct interaction with older adults with developmental disabilities than elsewhere in my work/community services.
- I know now what and how I can get everything to help my daughter.
- I have accomplished speaking up, telling my story.
- Stronger volunteer and better equipped to work directly with clients

What is one thing you need from the CoP?

- Job
- My services
- Clearer perspective on people's different experiences and needs in this community.
- Support to help promote inclusion and community integration of people with intellectual disabilities.
- Disabilities Person Civil Right
- Support from experts or councilors in the field of housing for people with disabilities, we need housing.
- To be sure that all agencies, services our mayor/counsel are aware of "the work" I am advocating for (Watch CIDCRRRA) etc.

- Information, more connection, more time to share how we are individually working (to build networks/connections).
- How to obtain speech communicative device?
- DC Government behavioral health assistive housing in young people with disabilities
- To figure out a way to protect people in DDS system (in group homes) who don't have families- and not through the "guardian" system
- How can you get better support with transportation?
- I need assistance changing policy on IEP accommodations after High School for a student who has graduated with an IEP certificate and still needs to learn to read and get a diploma through adult Ed.
- Support outside of group.
- Comprension por que los Hispanos somos timidos (Translation: Understanding that Hispanics are shy.)
- Mas informacion acerca de los protectos. (Translation: More information about the projects.)

Notes from Discussion with Andy Reese, Interim DDS Director

- BSA & Jared - Rent caps – people forced to move when hit it
 - Shouldn't have to move out of apartment and especially not into a group home from an apartment
- RSA – takes too long to call you back
 - Cases closed and need to start over
 - Call supervisor
 - Voicemail full
- RSA – What if 13 and half child with disability – how to connect RSA to the school for their child?
 - School is responsible to invite. Parent should prompt.
- DCPS is working to start transition planning at childhood
- RSA closing cases – because not interested in employment anymore, or can't get a hold of you, or you are employed and don't need help anymore, or you need more training or equipment
- People can come back to RSA – need to determine eligibility again
- What should parents know about RSA?
 - RSA primary goal is to ensure people with disability can engage in employment and RSA supports are temporary
 - Post-secondary success in the form of independent living and employment

- WIOA includes pre-employment transition services (PETS) – 5 areas
- Does funding limit the amount of time you can get RSA services?
 - RSA gets money from Federal government with 4% match from DC with limited funding, order of selection can go into place meaning a waitlist can happen and then people with most significant disabilities are served first – process is still the same – eligibility is determined and services are started if person is eligible and there is not a waitlist
- For people in their 20's who didn't get PETS, what can RSA do to counsel people through the process?
 - People should be counseling appropriately if they aren't and case is closed, you can appeal case.
 - We should have an integrated workforce system – RSA does
- Many people not aware of everything available and people in DDA relying on SCs and SCs don't always know what to do
 - SC's should have a better understanding of RSA
 - Providers should have a better understanding of RSA
 - SCs and V counselors need to work better together
 - We agree!
- You can always appeal an RSA decision and PSA is working to change the policy that says you can only change your major once.
- How are RSA counselors evaluated?
 - By successful closure (i.e. someone has a job)
 - Quality