**Community of Practice**
**for Supporting Families of Individuals**
**with Intellectual & Developmental Disabilities**

# D.C. Community of Practice State Team: Supporting Families of People with Intellectual and Developmental Disabilities Across the Lifespan
## August 27, 2013

Supporting families, the language change does matter, supports to families is different than family support programs

**CoP**

MLF: How states are setting up policies so people can be self-directed. How are families being supported so their person is fully engaged in community. Over 50% of people are supported in their home. And families are there through the whole lifespan. Partners, UCEDD, P2P, Sib, HSRI. This is our intensive learning. DC is the first one! Community of Practice means, we want to put framework together, going to work with all 6 states to identify agency collaborations and policy and practices to support families. Families care for and about the most. This is about empowering self advocates. We need to think about policies and funding different. We need to think about the future. This grant is five years, six states, MO is our mentor state. We've got east coast, west coast, urban rural. Had to have partnership between DD agency as well as council.

SR: Worked with self advocates for over ten years. They have taught me the most. PHD focused on families and partners in policy making. Families and SA have dreams too. Field is not helping project goals, things aren't just for the here and now, for adult outcomes. Inclusion is not enough, need to be connected and help understand. Resource center to work collaborative across MO. F2F network represents 95 orgs in MO. Have to present a united front, seamless message. Trying to understand informational needs, leadership needs, as well as goods and services. Family movement for the past 50 years. 1950 first documented family support movement. Families were figuring it out for themselves. Self advocacy movement in the 70's was a rebellion against institutional movement. In response, we created our state service systems. In the 80's, was when HCBS waiver systems were started. Hard to believe that there wasn't funding until then to help people live in the community. Family movement in the 50's was really the mom movement. We have slowly added other family members. Not the parent movement. The movements now are focusing on self determination. That is the older generation of SA. The generation of youth graduating now are fully included in school, and they are growing up and wanting different outcomes. Our field has evolved and changes, from medical to institution, to ICFMR, to group home, now to independent individualized supported living.

Self directed, individualized services and supports. There is an evolution happening in each movement. This national initiative is an opportunity to bring them all together. CoP is an opportunity for formal systems, self advocates, and families to come together share ideas to decide what we want. What is it we want, not based on our current system. We are thinking about the ideal world, and how to move the movements toward it. SYsems and formal services are based on eligibity.  Want to ask what do families need, not what do our families who are eligible. Only 25% of people with disabilities are known to the states. The other 75% are figuring it out on their own. We can learn a lot from the 75%. What is working and not working that we can learn and teach others. Keep in mind, all families, all ages. The 100%.

Family support programs started in the 90's. The program states that the reason the program exists is to delay families putting their kids in long term care settings. Should support families because it's the right thing to do. Across the nation, if you have a child or adult move into residential serivcies, they are there for a long time, and it costs a lot. Our numbers are going up .Had been reported 1% of pop, but new numbers report as high as 12-15% of pop. We automatically jump to the paid things that families need.

Wingspread, leaders from all over the nation came together to define family support in the disability world. Keep families as well as SA in mind. Wingspread def, national definition of supporting families. The reception of this definition has been positive. First time to see some unification of movement. Also defined three buckets around supporting families; information and training supports, mental health and self efficacy, and instrumental supports. Families getting info from other families is the key to real lives.  We all recognize the importance, but don't see it as our job. Trying to create a sense of community. Doesn't cost any money to refer a family to a parent to parent in your state. Give us info and examples so we can disseminate it nationally.

Have to recognize the roles of families. Families are vital. Families have unconditional love. Families care for and care about their individuals. System often does not recognize familial roles. So important for PWD to have people that care about them in the community. We are not just talking about financial or day to day needs, thinking about all the roles.

## Real life

Define a successful adult: house; car; kids; family; money; self sufficiency; education; career; good citizen; being happy; friends; personality; skills; independent; housing; spirituality; determination; doing things we want to do; community; it's ok to fail; have risk. We are all striving for, may not really achieve all of them, and we never stop. Why do people with disabilities have a different list than anyone else? Quality of life is quality of life. Strategies may be different for people with disabilities. Why are there higher expectations for kids with disabilities. What about natural consequences. We should have the same outcomes for adulthood. This grant is helping systems say, people with disabilities should have the same life and outcomes as everyone else. We talk like things are final. We move, we get new jobs, our field has convinced families that where the child lives and get a job at 18 is where they will be for the rest of their lives. Transition services expects kids to know what they want to be when they are 18. The rest of us have lots of paths to lead to what we want or don't want.

We all call our parents for ever for advice. Your family comes and goes as you need them. They don't do all things for you at all times. For PWD in family home, they are all all the time. There is evolution of families. Kids move out. Natural pattern of life is not natural if the child lives with the parents for ever.

Really talking about individual life outcomes. What have you done in your life to move towards happy adult outcomes? Early childhood: guidance from parents; eating habits; culture and tradition; helping siblings; discipline; respect; love; empathy; self esteem; sharing; time management; responsibility; rules; assertiveness; getting along with others. Schoolage: developmental skills; get responsibilities, baby sitting, chores, etc; volunteer opportunities, learn to travel alone, socialize with others; sports and extracurricular activities; study; communication; social skills; goals and deadlines; decisions; dream; money; take risks; consequences. People with disabilities also need these things to have adult outcomes. Often, families can't see the adult outcomes.

This is lifecourse thinking, different stages build and impact each other. When do people start engaging about employment. Ask kids with disabilities what they want to be when they get older, give the chores and responsibilities. All of that early in life leads toward employment. Do they get an allowance or have chores. What is the trajectory that you want? What are we doing as a field to move the trajectory toward real good adult lives. Our policy trajectory is not sending people toward an adult life. Social security example. Think about trajectory on individual, professional, and policy level. Even pediatricians and OB's can set the trajectory, they need the info too.

Can't forget real life conversations. Can't be all about the formal services. Teach teachers and para etc. to do that. Anticipatory guidance, changes the trajectory of lives. Guide people to a real life.

**Formal systems**

Early childhood: early stages; Head start; strong start; pre K; Child find; day care. School age: DCPS; charter schools; non public; private specialty schools; SPED; home schooling; Keen; Special Olympics; Spots plus; HSC; OSSE. Adulthood: RSA (voc rehab); DDA; Independent living; metro access, MTN (transportation); Quality trust; providers; Colleges and universities; vocational training; NGO; day programs; PNA; lifeline partnership. Aging: AARP; Office on aging; ADRC

Pie pieces are parts of people's lives. Must think outside their piece or stage in life. Teach so that people can be independent as adults. Not just about the now. Changing the conversation. Getting everyone in the room together. All pie pieces should have goal of adult good life. This will grow, you will invite more an more people from all the pie pieces and from across the whole lilfespan. How you coordinate across these will help people have the lives they want. Families say they need seamless services. Folder example. Need city wide connection to health care and schools. Have to remember we are not just focusing on kids and early childhood, there are adults that need this info and supports too.

**Families**

Early childhood: Health services for children with special needs; interagency coordinating council; Quality trust; PTI- AJE; family voices; family matters; parent navigators at children's hospital

School age: focus groups; families almost have to be experts to find and navigate the system, huge gap in communication, more word of mouth than anything, families are often in crisis; schools don't even have transition specialist, need to have assistance to make transition plans; public charter school need to be in the room

DC tends to be informal, people get info from word of mouth. Families have to learn what to ask for from other, but there is no formal way for this conversation to happen. Needs to be partnership so that families don't have to figure out on their own. If your doctor doesn't help you figure it out, you have to do it yourself. Have to have people who are decision makers. Everyone has been at these kinds of round tables before. The point of the five year grant is to push and assist with implementation and application. Navigation is necessary. Framework graphic overview.

Laura- Director DDS. Reason we applied for this grant, we have been having this conversation for 30 years. So much is disparate and informal. DDA has been consumed by a class action law suit for the past few years. Recognize that there is no agency dedicated to coordinate services, that is a real weakness in DC. In 2010, 11, and 12, the DD reform act was introduced in DC. Key to legislation; opening eligibility to DD, not just ID; recognizing family support; open DDS DDA to a lifespan agency, after part C. That legislation did not go through due to financial implications. Trying to bring back the DDRA, then the grant came along, such a great opportunity to bring families and organizations to mobilize the agenda forward in DC. Would like to make a family support waiver. How can DDS become a coordinating agency for lifespan services. Lots of leadership support and focus. Dedicated to this effort, this grant is going to help guide us and offer national best practice.

**Three indicators that we would know this grant was successful at the end**

- Better transition to adulthood
- Programs come together, at the table, stop the segregation, start sharing, coordinated and integrated services
- People are living the lives they want
- Culturally and linguistically supporting families
- Identify and fill gaps in formal supports across the lifespan, meeting all needs
- Policies informed by stakeholders grassroots
- Information infused across, where people can access it
- Professionals are knowledgeable and influence a good trajectory, workforce capacity building, professional development.
- Positive mindset/reaction
- Doctors and families who are educated on resources and education as well as adult life choices, being aware of local state and federal laws
- Families are truly educated about choices, they know how to talk to professionals, don't let people tell you no all the time
- Don't just give families the next eligibility step, give families pros and cons so they can make the choice
- Essential to create a policy or guidance for family engagement
- Develop a network of families that provide support to other families

- Believe that intensive early intervention does change a child’s future
- Stop limiting child’s future, you are raising an adult, not a ‘cute’ child with ‘cute’ behaviors
- Develop a network of all partners, so the info can be given to parents so they can easily move through services, seamless
- One stop shop for resources, and a network
- Have more permeable boundaries between families and agencies. You don’t give you person to the agency.
- Counseling services, especially for crisis
- More venues for families to meet
- Instead of a long cycle, go straight to the leaders, give them the right message so that they can make the changes. Good quality of practices.
- Have more sensible transportation through the whole city, more accessible
- More housing options, apartments and homes that are accessible
- Seamless services, one stop shop
- Engage communities and families and individual supports
- Family centered service delivery- family centered from cradle to grave
- A neighborhood based support network that controls the allocation of paid services in their communities.
- More advocates, doesn’t matter what ages
- More families coming together, churches also come together
- A parental force to address officials, a consistent group, show that we are working to make change
- Getting schools more involved in pushing our children to independence
- Childcare and aftercare for kids with dis
- A family support resource call center, one place they can call, not a directory, but a place to call and get resources, be the same place you are going all the time, this center would be the knowledgebase
- Meaningful vocational and career planning that does not always tie to a bachelor degree
- Should have services that are coordinated and comprehensive of supports across the lifespan
- Family to family, parent to parent
- Create a seamless system
- More parents and professionals are accessing and navigating services in DC
- Develop a parent to parent group/network
- Establish more formal service an supports for adults
- Collective work supports people to self direct and a good life
- DD not just ID

**What are threats to project success?**

- Don’t bite off more than we can chew
- Lack of Parent participation
- Negativity- attitudes and people

- Lack of commitment- agency and personnel
- Person vs person; agency vs agency
- Only talking not action
- Lack of trust
- Territorial behavior
- Lack of commitment
- Lack of communications
- Lack of funds
- Lack of belief in the possibilities
- Not fully integrating families in the system
- Only as strong as weakest link, all necessary agencies must buy in
- Leadership must believe
- Change is a process
- Next lawsuit
- Lack of leadership
- Not engaging self advocates and families

**Who should be invited to the next meeting?**

- Members of congress
- President Obama
- Dept of health
- Mayor's office
- Dept mayor for ed
- State board of ed
- DCPS
- RSA
- Mental Health
- Office of African American affairs
- Neighborhood councils
- Elected officials
- American academy of pediatrics
- Charter school board
- Police/EMT
- Medicaid office
- DCDS
- ALL the schools
- Children's medical center
- More council members
- Office of Latino affairs

**Concrete next steps**

- Who needs to be invited
- Next meeting
  - Monthly would be better, keep the momentum going
  - Switch up timing, maybe evening and weekends, webinar
  - Make a plan of action
  - Create subcommittees to drive the work
  - End of September
- Be creative and engage in lots of ways
  - Communication team?
  - Categories so people can keep up on the things that they are interested in
  - Don’t always have to bring everyone here, need to get the words, not the people.