



**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**

***Comments from DC Kick Off Event***

***Comments reflecting Values or Principles***

- Believe that intense early intervention changes a child's future – (no wait and see attitude, address it now)
- Always remember you are raising an adult, not a cute child with cute behaviors
- Stop limiting a child's future. shoot for the stars for each child regardless of labels
- Successful adult live means different things to different people with different backgrounds. What really matters is that adults have the options to pursue the outcomes they want
- People are living the life they want
- Programs to work for families so that they have better quality of life
- Create the vision of adulthood and integrate it from the beginning
- Our work thoughtfully supports people and families self-direction to a good life

***Comments reflecting Leadership***

- Leaders in general know what is happening
- Leaders need to be aware of quality of services
- Inform all parents about the supporting family program that will be developed for community

***Comments reflecting supports to families:***

- Developing and establishing a Parent to Parent network in DC across the lifespan
- Parent support/resources/call center for all questions – lifespan
- a formal city wide cadre of families that provide parent to parent supports to other families – City ambassadors
- Develop a navigation network that parents can go to with all partners for information and directories are made available
- A support line for parents to call in when there is stress and he/she used to reach out and speak with someone

- Venues or means for families to meet
- City wide bank of resources for families to access (no matter the place they are in in their journey)
- Have parent to parent support, especially formed on transitions across the lifespan
- More advocates and families come together
- Information infuse across system where families can access it – located in schools, hospitals, etc
- Peer connection for parents, siblings, self-advocates and any other family member
- Development of Parental Force to address political officials about the needs
- Families that truly have been educated about choices
- An official book that contains all services (updated) that DC residents can participate in when they have children with special needs
- Strong meaningful presence of families at decision making level
- State wide support groups

### ***Comments reflecting access to services or supports:***

- Coordinated
- Seamless
- One stop shop for families
- One agency that GUIDES a family
- There is a designated DC agency to coordinate lifespan services and supports for people with ID/DD and their families
- More parents and professionals are accessing, understanding and navigating early intervention
- Educational and family support navigators are available to families in DC
- Easy access at any point regardless of age and disability
- One-stop shopping for families and individuals
- Easily available information for families
- All relevant services are at the table (medical, social, education, advocacy) for the lifespan
- A seamless path of services from early intervention to aging – coordinated and integrated services
- One central place to find assistance with resources
- Seamless system for families – easy to navigate
- Improve access to communications

### ***Comments reflecting Services in five years:***

- Coordinated agencies, non-profits, families, persons with disabilities
- Support creative and informal support options as well as formal
- Supports shaped by people with disabilities and families that focus on outcomes
- Systems in place from birth to adults to help them be self-sufficient (health care, schools, etc)

- Neighborhood based individual and family support networks that control resource allocation of formal services
- City wide policies or guidance for family engagement
- More person and family centered
- Identify and fill gaps in formal support networks across the lifespan
- Good Quality and Practices with accurate strategies to communicate
- Systematic issues being resolved
- Policies are informed by stakeholders
- Coordinated services
- Seamless partnerships with families, agencies and communities
- Cradle-to-grave service delivery that is family centered (Part C-esque)
- Establish family services and supports of District residents with DD (without ID as primary diagnosis)
- Excellent culturally, linguistically competent means of communication to and between families
- Recognize the role of families in supporting adults who transition to new residential services
- Comprehensive system of support across the lifespan and include P2P networks for grassroots family supports
- Counseling services – ideally some free for families in crisis
- Better transition for youth to aging
- More organizations/companies offering disability services

### ***Comments reflecting Community and Life Outcomes***

- Engage communities in family and individual supports
- More churches come together
- Better housing
- Transportation
  - Accessible transportation throughout the DMV area
  - More accessible apartments/houses
- Employment or Economics Sufficiency
  - Better jobs
  - Money for Adults with developmental disabilities
  - Meaningful vocational career programming in schools and secondary education, collages, tech schools, etc
- Daily Life
  - Schools improved and increased support services for students
  - Training for DCPS charter schools to deal with children with special needs IEP's (appropriate goals)
  - Childcare/aftercare for students
- Medical:
  - Knowledgeable docs, service coordinators, teachers who encourage a positive trajectory

- Doctors and families who are educated and informed on resources, services, education and adult life choices (especially local and state and federal laws on disabilities)
- Network of Health Care professionals who service individuals with disabilities