What is working and not working for people with intellectual and/or developmental disabilities and their family members in DC?

| What’s working/What makes sense? | What’s not working/What doesn’t make sense? |
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| * HSCSN Services
* Home health PCA services (IDP Waiver)
* Advocate to help with RSA
* Being a strong advocate gets thing done – persistence
* Being listened to by some service providers (new ones)
* Transportation with aide and driver my family member gets along with
* Early services in elementary school were good
* One-page profile! Especially for doctor’s visits
* PCT tools for student – led IEP meetings
* Women’s knowledge group, women with disabilities talking about relationships, dating, etc.
* Georgetown trains nurses on sexuality
* Having a teacher or educational program that is inclusive by design – charter school with sensory breaks and integration taken care of.
* Yachad (Re-building together) 202-296-8563 – Was an extremely valuable resource in assisting me in creating a wheelchair mobility space for my husband to include walk-in shower. All of this work was provided with on expense to me.
* HSCSN has respite hours for caregivers/clients. It would be nice to see this spread to other MCO’s
* Transportation generally works OK
 | * Hoyer lift training for caregivers
* No coverage for people with developmental disabilities who do not also have an intellectual disability – there is a waiting list
* Conditioning of professionals to say what they can’t provide
* Having to get a second opinion to get what is needed.
* Having to pull child out of school to get services because school not providing.
* Getting services providers to think out the box and try new things.
* Always maintaining course of action instead of changing things when necessary.
* Needing to have IQ of 69 or below to get services.
* “Old School” thinking-making the person fit the system rather than the other way around.
* Communication and person-centered thinking not working how they should.
* Not listening and paying attention to behavior.
* Navigating social security – so much paperwork.
* Not a good level of understanding of social security by local service coordinators or providers.
* Getting services for someone who doesn’t qualify for SST or someone who only needs a little support, not enough need to qualify for nay services.
* Always hearing “No” first.
* Only doing what is required.
* Person Centered thinking not fully engaged.
* PCT outside of the adult service system.
* Taking on rights and responsibilities without knowing what to do or how to handle the responsibility – need to be supported in building skills to take on rights and responsibilities.
* Educational waiver at age 16 (not legal)
* Schools not recognizing an educational power of attorney
* Lack of understanding of power of attorney documents
* Schools encouraging guardianship.
* No resources on human relationships and sexuality in DC
* Not respecting adult’s rights to intimate relationships
* Adaptive equipment at recreation centers not working sometimes or it doesn’t exist outside of therapeutic recreation center.
* Childcare for kids with disabilities.
* Getting support in the community outside of family members.
* No good inclusive summer camps.
* Assumptions that people can’t do anything.
* Service gap for people with DD and not ID.
* Not having services coordinated out of one agency – would allow for a true life course framework for support.
* Need for continuity throughout the life course.
* Parents being on their own to navigate systems.
* Missing supports for people who are in supported living program on home visits with aging or disable parents
* A lot of school staff don’t read our kids paperwork in their file.
* Stop the courts from making decisions
* Parents and family members of individuals with disability need rights to make decision even when person with disabilities are adults and present family members can no longer care for them.
* The service provider for PCA services need to understand the need for continuity of care and that some clients will need more than medical services – they may need mental health support and should have trained staff to support that need.
* ABA therapy program is needed in our DC schools for our children with Developmental/Intellectual disabilities.
* No one listens to your family members needs until you bring in an advocate/lawyer – Why? This has been true, since early intervention.
* Alliances and shared practices between organizations – ex – a student at DC charter was missing 60+ days of school every year. He was a low functioning non-verbal student with Autism. He was missing school due to the fact that he hated transitioning and would fight, bite and hit his mom. The school’s position was that because they has services every day for each particular age-group, , that they made services up for him when he was in school. His insurance backed by his provides authorized the parent to place him in residential buy she needed to follow-up with DCPS to pay for his education. They refused for the reason listed above. The student also had ODD and was refusing his meds.
* Communities that is not educated on people with intellectual/developmental disabilities.
* DCPS education/failing to educate our children with developmental/intellectual disabilities
* (ABA) Applied Behavioral Analysis is needed to work one on one with children with developmental disabilities
* Coordination between DDA: HSCSN Network 18 – 26, especially at 22 when school services end.
* PCA Services for persons with developmental/intellectual disabilities who also have behavioral issues due to mental health issues.
* Person shuttled from agency to agency because they don’t have the capacity to care for them. They may insist on the person being medicated in order to keep services even though medications may not be effective in curbing the difficult behaviors.
* No resources for support for caregivers of persons who are not children (school aged) or seniors
* There are only 2 agencies that have services for transitioning youth over 21
* My son’s service coordinator was changed and on one notified me until I called.
* I seldom hear from her unless I call. She makes a list of my requests but doesn’t do very much about them. My son is 43years and I’ve been asking for a vocational assessment since he left school and it hasn’t happened.
* He receives respite under the waiver but I had to take him from NE to SE to access it.
* Appropriate transportation
* Person Centered services
* Dental services
* Medication procedures
* Time line for resolving issues with providers and DDS
* Cumbersome Health passport
* Training for transportation providers and their employees
* Thursday nights to the chateau sometimes a problem. There was a time when they didn’t show up at all.
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