What’s working and not working about Supported Decision Making in DC right now? How do you support your family members to make decisions? What barriers to you run into when trying to support your family members to make decisions?

| What’s working/What makes sense? | What’s not working/What doesn’t make sense? |
| --- | --- |
| * + - * Power of attorney in several areas is working. Power of attorney is a shared agreement – it can be revoked at any time       * Formal and informal agreements for SDM – having options       * Having opinions and decisions respected by professionals       * Incorporating my child into her IEP process EARLY – age 9       * School staff receptive to one-page profile       * Being patient with the learning process of how to include my child in her IEP – both her learning and staff learning       * Having patient and kind help from professionals to understand things that are confusing       * Showing proof (like a video) to professionals that my child can do certain things       * Working with children early on – as babies to teach decision making – parents and professionals can do this       * Being believed in by my parents       * Being involved in advocacy to educate       * OSSE and schools teaching self-advocacy more       * Efforts to educate children about their own disability – video being used in one of the high school       * Smart 911 can be a resource - you can put your child in this system and say that they can’t be questioned in an emergency without their supporters       * Asking pros at meetings to say positive things about my child and say negative thing more constructively       * NOTHING ABOUT ME WITHOUT ME!       * Angel sense GPS tracking device - $39/month       * Conflict resolution tools can be good! Having a 3rd party who can facilitate disagreements between families or professionals – need access to this and training       * Family therapy helps with conflict | * + - * Being asked to sign away educational rights at 16       * Being told guardianship is necessary from professionals who do not know my child       * There are not enough learning opportunities for people with disabilities to learn how to make decisions or for family members to learn how to teach this       * My child was not invited to her own IEP meeting by school staff       * Having goals in the IEP that my child has already accomplished       * Still need viable options for SDM – an understanding of the formal and informal agreements – guardianship, power of attorney, etc.       * Deficit based meetings       * Hospitals not acknowledging decisions by people with disabilities without guardians       * Assumptions that people with disabilities are not competent to make decisions       * Doctors not talking to me at appointments       * Testing – need support in making decisions about whether or not to have children tested – eventually this leads to capacity tested       * Having clinicians assessing people in a way that limits their life and future decision making options       * Not having enough support for how to teach decision making – We need a Tip Book!       * Need information on how to work with police to understand these issues – is there any legal standing/would need in the event that my child has an interaction with police |

What would you need to feel safe in using supported decision making outside of guardianship? How can we all ensure safety and support independence for our family members with disabilities?

* Need support from other parents as I am learning how to support my child in making their own decisions and being independent.
* Need a change in mindset - let’s change the way we think about people with disabilities. Encourage the mindset that it’s ok to make mistakes – exposure to decision making important. We all need decision making support and people with disabilities are no different.
* Need EVERYONE at the table together creating solutions for SDM.
* Need trust between families and professionals.
* Treat people the way you want to be treated.
* Make sure people have robust support networks that are consistent and ongoing – be intentional – how do we do this? We all need to create a Tip Book for parents on how to do SDM.
* Always ask WHY! Encourage all supporters to do this to support people in thinking through their decisions and establish open communication.
* Need multicultural and multilingual supports
* Need to build relationships - the community keeps you safe!
* Need to start early with teaching children how to make decisions.
* Need access to conflict resolution.
* Need to end commitment that affects some people with moderate to severe intellectual disability – It is hard to get un-committed because there is no re-assessment of capacity.
* Need to learn skills in setting boundaries
* Need trust that professionals will welcome family supporters into the process, even without a legal document to require it. There is a fear that we won’t be included when professionals don’t HAVE to invite you.
* Need training for everyone – families, professionals, the larger community
* We all need to raise expectations/build exposure and experiences.
* Build networks of supports in the community (i.e. circle of support) that the person and family trusts
* Need to support people with disabilities to learn and engage in advocacy and self-determination
* Learning for family members on how to ask for help
* Opportunities to be independent from a young age
* Intentional community integration/relationship building so people know your son or daughter at neighborhood stores, coffee shops and other establishments.
* Need to involve the faith community
* Recognize we are all interdependent!
* Opportunities for community education – teaching people how to connect – by people with disabilities and families.
* Having trusted people who your adult child can reach out to for support
* Make sure respite is available so there are opportunity for kids to be away from family and for the family to regain perspective.
* P2P and peer support
* Sharing resources

What are all the doors people with disabilities and their families come through looking for support? Where are the places we need to raise awareness about supported decision making?

* Department on Disability Services
* Schools
* Hospitals
* Social Security Administration
* Providers
* Nursing facilities
* Police
* Insurance companies
* Banks and financial institutions