

Notes from DDA Listening Session #2: Hagerstown, Maryland

October 23, 2014

Family Session

This session was one of a series in each of the four regions of the State. There were separate listening sessions for self-advocates, families and providers in each region. Across all of the meetings, a number of themes emerged. These included the following:

- *A desire for more frequent and understandable communication with DDA (both in writing and in person)*
- *A need for improved Resource Coordination (emphasizing the skills and activities that are important to the individuals and families served)*
- *A concern that the system lacks trust at all levels, and a strong desire to build partnerships (between the state and self-advocates, families, advocates and providers)*
- *A need for improved consistency and staff capacity at DDA*

The feedback at each of these sessions was thoughtful and impassioned, shining a light on the need to work together to improve the system for individuals and families.

In each session, the facilitators asked the following questions:

What things are going well?

What are challenges/barriers and/or things you would like to change?

If changes are made to the system, what are things that should be kept?

The notes below reflect the feedback from the session participants. In some sessions, the comments mainly reflect areas where improvements are needed.

Areas for Improvement:		
	Requiring respite provider to be an employee of an agency makes it very complicated (not to be able to access neighbor and other flexible means of supports). Having a person go through agency trainings to provide support does not always makes sense and limits the amount of people who can provide assistance/respite.	
	Overtime complications to respite.	
	Medical admin/nursing oversight requirements limit support and take a large chunk of budget.	
	Respite is not flexible anymore.	

Areas for Improvement:		
	Support services are being forced into institutional models.	
	Communication between Autism Waiver and Community Pathways is confusing and not seamless for students exiting one waiver and entering another.	
	Gap in transition services- DDA not starting when person leaves school/not always starting on July 1. Family had little notice as to when supports would start.	
	Self-advocacy is difficult. Hard on families to explain to their loved ones that they probably really can't live on their own. Balancing reality vs. hopes and dreams. Families need to have a say in decisions.	
	Giving balanced information to individuals (i.e. one person was told they can get emergency services if parents die).	
	DDA needs to hit the needs of all individuals with different support needs.	
	Feels like DDA holds services hostage by making us jump through hoops.	
	DDA control and barriers get in the way of supporting value.	
	Loss of value of person centered thinking and support.	
	Service coordination doesn't have competencies- they do not provide help and supports.	
	Three months to get a service funding plan completed and delays.	
	Systemic problems within DDA that go back decades.	
	Fiscal impacts/cuts hurt the DDA system – this is a Maryland state issue.	
	Rules change at the end of the fiscal year to make it so individuals cannot use money. Feels business like instead of person centered.	
	Portability of funds across state lines.	
	Families do not have access to plan costs (information not provided).	
	Services dropped at will when funding runs out.	
	Access issues - If someone is getting nursing services	

Areas for Improvement:		
	they cannot get other DDA services. Families have no idea where to go to for assistance. No assistance- if you get REM you can't get LISS	
	Interaction with Service Coordination is not genuine. Paper pushing only.	
	Going from Autism Waiver to DDA was a tremendous cut in hours.	
	Need the right staff, need to be secure that the services will continue.	
	Lots of layers to services, lots of waste.	
	Families would like a choice as to whether or not they need a service Coordinator or if they would like that money put into direct supports.	
	Fractures between Medicaid and DDA (No cross system coordination).	
	Differences between Medicaid and DDA regarding what nursing duties are permitted.	
	We've put pen to paper during this meeting but will that alter the bureaucratic methods in play?	
	System writes rules without understanding the impact on people and their families	
	What part can families play in advocacy? Families want to be more involved.	
	Schools- families have to focus on deficits- not on success.	
	Need jobs- few employees in the state (and some employers are leaving.)	
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Notes:

General discussion and/or information not included in specific comments:

Families wanted to know when they would see the results of these meetings. They wanted to review the notes and wanted to know when they will be worked on with DDA. They do not feel that change will occur.