

Notes from DDA Listening Session #3: Columbia, Maryland

October 27, 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:		
	Transitioning youth (especially for individuals with autism) are not getting the 1:1 support they need. If they do get it and are successful, the supports are taken away, leading to a cycle leading youth to have to fail. In addition, there is no inter-agency collaboration which serves as a cliff.	
	Providers are stretched, there is not enough capacity, and DDA should be encouraging growth and simplifying so that providers can support individuals (including those with complex needs).	
	DDA is not clear on goals and has not established	

Areas for Improvement:		
	structures (services/payments) to further community integration.	
	<p>There has been a poor job of promoting self-direction:</p> <ul style="list-style-type: none"> - Help people to recruit, manage staff - No provisions to give staff vacations or benefits - Individuals are not well trained on staff interactions (including discipline and/or firing when needed) - The role of the support broker is unclear - The available information (especially about support brokers) is very out of date 	
	Families are feeling that they have to “fight” for everything.	
	Families have experienced times when DDA says “you have 10 days to find a residential service provider. This had led to bad outcomes for individuals, but families did not dare to miss the funding opportunity.	
	<p>Challenges with services:</p> <ul style="list-style-type: none"> - Staff need better training/support - Behavior supports are difficult to get and, even if you can get the behaviorist’s time, there is no opportunity for the staff to be trained. - There is a fear of retribution if you complain too much - Need stronger DDA management and provider - Need expectations for providers to talk to each other coordinate (even with it is the same provider agency, sometimes day and residential communication is a challenge) 	
	<p>Within self-direction, there are some important items that are not covered:</p> <ul style="list-style-type: none"> - snow/ice removal <ul style="list-style-type: none"> - Lawn care - Other essential chores - Transportation a challenge, too 	
	<p>Person needs to have the opportunity to choose who they hire, including if they want to hire family.</p> <p>There needs to be a greater emphasis on families</p>	
	There are significant problems with resource coordination. RCs do not have skills needed to do the job. (this is a change from the past)	
	There should be a greater emphasis on building a team and working collaboratively. Focus seems to be on process currently.	
	DDA customer service is not strong	

Areas for Improvement:		
	For individuals in self direction, there needs to be adequate support for minimum wage and benefits.	
	There needs to be greater communication and staff retention support/efforts.	
	There needs to be better training for families and parents, to educate them on what is permissible (for instance, they should not sign blank timesheets).	
	There should be greater public information regarding provider audits. This should be publicly available to inform choices – sometimes agencies should not be allowed to accept new individuals.	
	There was concern expressed related to cuts to day service hours, to the locations of group homes (too many concentrated in same neighborhood/street).	
	Many individuals in the room expressed concern about the complexity of DDA. So many layers that it is hard to get anything done and the focus seems on process not people.	
	Role of the RC is unclear – they are not building relationships with individuals and often families worry that they are only doing paperwork. DDA should support quality and stability.	
	DDA's response to emergency requests needs to be improved.	
	There was a recommendation to include bridge support to help individuals get housing.	
	The person-centered planning process needs improvement.	
	DDA should help families network with one another (this was a widely held concept at the meeting). This is especially important for families who are engaging in self-direction so that they can learn from one another.	
	The fact that day program and supports are mutually exclusive is a problem.	
	In self-direction, individuals are not able to get behavior supports.	
	LISS –problems with moving money and this places a huge burden on families (related to camp, especially, but not limited to that).	

Areas for Improvement:		
	One individual advocated for portability of service dollars. (She noted across state lines).	
	The RFC process is way too long.	
	DDA has to stop saying that “we don’t serve kids” and “we don’t serve families”	
	There needs to be better training of DDA staff – recommendation that DDA staff have experience working with individuals with disabilities.	
	Communication is lacking from DDA and is sometimes incorrect.	
	DDA needs to partner with other organizations to help them with their mission –and to help get clear information out to individuals and families.	
	The reasons for denials are never clear and do not seem consistent across the state.	
	There was a strong recommendation from the entire group (very full room!) that DDA should commit to actionable steps from these session and report on progress in a way that is easy to track.	
	DDA should foster the connection of siblings and families.	
	Recommend considering an ombudsman approach to support families – and to protect families from vindication.	
	DDA needs to build in communication, coordination and accountability – do not pay if performance is poor	
	There was concern about what the CMS rule will mean in Maryland, fear that individuals will be left without services.	
	There was a recommendation for a hotline when individuals and families have concerns.	

Notes:

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

There was a great deal of passion in the room from the families in attendance, with large concerns threading throughout the discussion on the complexity of the service system, the lack of consistency across the state, and the need to build the strength of DDA and key partners such as resource coordination. There was a strong sentiment that families feel that they need to fight in order to get what they and their son/daughter need. There was an overwhelming sentiment that DDA needs to engage more with

families, so that there are relationships established and to ensure that DDA understands the individual and family perspective as they consider policy options.

At the suggestion of a number of participants, a number of families provided their emails in order to connect with one another at the session. DDA will be sharing this information among those families who indicated their interest by signing the sheets provided.