

## Notes from DDA Listening Session #1: Bowie, Maryland

October 22, 2014

### Self-advocate 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:		
	Things are overly complicated; communication needs improvement; people sent running in circles.	
	Families are not having access to the information they need to secure the services needed for their family members.	
	Telephone system is almost as bad. Too much time spent going through menus; very frustrating.	
	Things are overly complicated; communication needs improvement; people sent running in circles.	
	Concern about community choice waiver and what is available. Families are not having access to the information they need to secure the services needed for their family members.	
	Need to improve website. So confusing that you spend	

Areas for Improvement:		
	lots of time just figuring out what might be needed.	
	About 18 months ago started talking about New Directions and Community Pathways. Everyone said it would not affect her daughter's program (ND). She believed it until this year, but after submitting annual report, it took them 2 months to call and tell her there was a problem and they would not approve it and it had to be corrected within a short time period. Does DDA need more staff? Is this a problem because there isn't enough DDA staff? Maybe lots of these problems are because of lack of staff!	
	DDA has a high turnover, so when paperwork is there, the next person doesn't understand, isn't trained properly to process the paperwork, etc. Training with personnel on how to deal with paperwork and things submitted to them. Took a year for them to say "resubmit" then six months later, "we can't find it." Need to make sure staff has the necessary training.	
	State can learn from federal government with regard to technology and forms being submitted. Stop back pedaling and move forward.	
	Things are overly complicated; communication needs improvement; people sent running in circles.	
	Needs improvement with the computer system. DDA doesn't accept electronic applications! Upgrade the system. Email application would also give a date stamp and paper trail, otherwise people have to send certified, etc. and keep a record for resubmission.	
	Things are overly complicated; communication needs improvement; people sent running in circles.	
	Concern about community choice waiver (The Arc-Howard), doesn't know how to work with The Arc to get the services she needs to support her sister. Told she has to prove what has happened with incidents. Wants to work with DDA to find a new group home for her sister. She wants to know how to file an incident report. DDA is not meeting her needs. She needs to find out what kind of services she can get to help her and her sister. Families are not having access to the information they need to secure the services needed for their family members.	
	Need to improve website. So confusing that you spend lots of time just figuring out what might be needed. (all hands raised)	
	Webinar a while ago on incident reports which need to be filed, but link didn't work, and then she tried to participate by phone, sent questions, but no one ever responded or acknowledged. Still doesn't know if she just needs to file three month report or has something really changed? Doesn't have access to training and received no response	

Areas for Improvement:		
	to question. Report hasn't been acknowledged.	
	When is training for New Directions? Have never seen it.	
	New Directions waiver needs to be completely revamped to provide information to families about how to really do this job. They come out of the sessions with some information but don't know how to go about doing this correctly.	
	Families need to be appreciated by DDA for the amount of work families do. Conversations are always negative (just out to get more \$, families stealing \$, etc.), and DDA does not seem to acknowledge in any way the amount of commitment and work families do. Tired of being the adversary!	
	How is DDA organized and staffed to be responsive to families and make sure they are responsive to changes they are requiring?	
	Terminology...parent received a 13 page questionnaire which used inconsistent language, talking circumlocution. Get to the point! Wants a glossary of terms...can't get by with half a book.	

Notes:

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

Families need to know where we go from here. All this data will be collected and presented and they want to be informed every step of the way. They want to know if DDA will respond to some of these issues or is this another rubber-stamp and questionnaire. Want to know that when our contract is over, who will follow through? They feel they have had the same experience previously with this problem. We need to do this work through the end of the calendar year, but continue then as a long-term relationship in an advisory capacity beyond. Need advocacy follow-up!