

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

October 22, 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:		
	Not enough information about anything, especially in writing. Families need information in their hands to make the best decisions. Serious communication gap especially after transition has occurred. Once into resource coordination, it's a once a year thing...people running through their paces and not getting enough information; push the paper through and get the process done. Meetings are more about paper than talking with individuals and their families.	
	Glossary of terms, not all this governmental wish wash! Need a common language.	
	DDA has been discriminating against people that are deaf. Not allowed ongoing sign interpreter for people that are deaf. Told: cognitive disabilities are primary but all other	

Areas for Improvement:		
	disabilities we don't have to service.	
	Concern: how to navigate the state website to get help; deplorable.	
	The use of SSN on every document—too many hands looking and using these numbers and identity theft is a problem. Need to stop using SSN and DOB. These are privacy violations. Someday in the future we will find that identity has been stolen and now they are ineligible for housing or something else they need.	
	Communication...is having a provider fair annually so we know what services and service providers are available. This doesn't happen after transition...black hole of space where you hear nothing. Need to build on the successes of other families, Learning from other families and building on their successes.	
	Disconnect between SS and DDA; families find themselves mediating between the two to settle the services.	
	Information not excuses.	
	Who does what and what are each person's responsibilities?	
	Instead of using full SSN, use only last four digits.	
	PG county has great transition services and fairs, power point how to get services, etc. but once the person has transitioned, it's all gone. Communication does not get out to families or to the public in general. Plug for parent support group at The Arc PG (ADDCAC).	
	DDA should make information available about meetings and groups in the community which provide information and support. People should have one place to go for this information.	
	I'd like to get my own place and want support for this. (Self-Advocate)	
	Big pushes for community integration, but people living in residential homes are not able to access their community because they don't have enough staff to support this.	
	Metro access for people in this area who are self-directed, you have to pay the money out first and some people can't afford that.	
	Community integration is supposed to be very important, but as its set up now, anything they want to do with a staff person, they are actually paying for two people. Requiring a support person, that fee should be covered.	
	SS will pay fees for college with waiver form, but not lab fees.	
	Community integration. Needs training and funding. It can't be stated as a goal without providing resources to make it available and make it happen. Continually reject	

Areas for Improvement:		
	going to college, paying fees for events, and other things related to community integration. No funding to support this goal.	
	Wants clear explanation of self-directed and non-self-directed services (response: in Medicaid home and community based services, there is a choice; self-directed includes hiring/firing staff, and a great deal more flexibility; under traditional model, provider agency is involved in providing the services. State identifies services available for self-direction and non-self-direction and often people do a bit of both)	
	People can't currently be in two waivers in the same time, but now you would be allowed to be self-directing some services and being with a traditional provider for other services if desired?	
	Need more information about the system. There is NO information, not just for transitioning youth.	
	Resource coordinators are not letting families know about the self-directed options; feel that provider agencies are "holding back" this information and support brokers are needed to navigate the system of DDA. Resource coordinators are supposed to provide information for informed decisions and they do not and they make it seem too difficult to self-direct.	
	Housing...everything low income has a 5-10 year backup. Need support finding affordable housing.	
	Until DDA has been in our shoes, they don't know what it's like. Children diagnosed with Asperger's = no help; must be diagnosed with autism.	
	In self-directed, move money after March unless health or safety issue, which means money goes unspent unless it's moved and what's the reason for this?	
	Graduating at 18 there is a gap in services until age 21 because the services aren't available. Lack of information about the process; punished for graduating "on-time."	
	Coordination of services varies from region to region and should be consistent.	
	Redetermination process is called the eligibility division of DHMH and they have major problems. As part of this determination, they determine how much the person is supposed to contribute to their cost of care. Changes frequently; haven't been following their own formula; have been asked to overpay and then to pay nothing. Impossible to talk with to discuss the issues. (several hands)	
	Asking for comments on the waiver but don't know what's included and so how can we comment on this?	
	Self-direction; was told son going to day center could not	

Areas for Improvement:		
	participate in self-direction. Is this changed? Uncertainty about what services are available for self-direction; is it all or nothing? Has this been changed by the change in the waiver?	
	Why can't you be eligible for LISS if you receive DDA services?	
	Especially for people using wheelchairs, CSLA cannot use the family van to transport; caregiver is allowed to use their car but not the agency's car; if caregiver doesn't have car, person is discriminated against. New Directions waiver is the only exception.	
	Self-advocacy training—referred to DDA contact for schedule. Challenges with capacity and information about when/where it will be and how to register.	
	Self-directed services need to have regional meetings of individuals who are self-directed to come together and share ideas. People have to do this on their own, which is difficult. Annual or quarterly meetings to we don't have to reinvent the wheel. Southern region did this previously and it was stopped.	
	Need better training for support staff. You get what you pay for. Need better salaries and training (also for resource coordination).	
	Concern: waiting list people, especially critical ones, are treated horribly. People are suffering financially and emotionally and the system is set up to have people waiting for years to get the help they need now.	
	Until DDA has been in our shoes, they don't know what it's like. Children diagnosed with Asperger's = no help; must be diagnosed with autism.	
	What is the state of Maryland doing for these people? What are they trying to do? (very upset) What is being done for the people in this room? Nothing. Shouldn't have to pay for metro access; it should be a given. Children are coming home at 5:30-6 pm in the evening after leaving day program at 4 pm. Embarrassing to come here to learn what needs to be done, when it should be on the website.	
	Once someone has a waiver and plan of service, still hasn't received services. (July to October) Too much delay.	
	Follow up on cost of care for people who have SSDI requires spend down and families are often unaware. Very complex calculations are changes are happening without notification or discussion.	
	DDA should make information available about meetings and groups in the community which provide information and support. People should have one place to go for this	

Areas for Improvement:		
	information.	
	Metro access for people in this area who are self-directed, you have to pay the money out first and some people can't afford that.	
	Follow up on caregiver using own vehicle; caregiver can jeopardize auto insurance by using car for work.	
	Staffing and transportation:	

Notes:

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

Families were very upset DDA was not in the room. They wanted to be heard and wanted to make sure we conveyed the true emotions in the room.

Although many participants were upset DDA was not present, a few participants did in fact express they felt differently and were glad to have the opportunity to speak without DDA staff present.