State of Maryland

September, 2008

DDA Director
Michael Chapman

Focus Group Input from Stakeholders:

Summary of Input

Developmental Disabilities Administration (DDA) Strategic Plan

DDA sought input from self-advocates, caregivers, providers, resource coordinators, and other stakeholders during development of the DDA strategic plan. The meetings were organized at the following locations:

September 18	Hagerstown
September 19	Largo
September 19	White Plains
September 22	Cambridge
September 22	Elkridge
September 23	Baltimore
September 23	Bel Air

Questions Included:

Question One: What has been successful for people with disabilities in Maryland to this point? What worked?

Question Two: What is not working in Maryland for people with disabilities? What are the barriers? What is missing?

Question Three: If you were the state DD Director for DDA, what would be the top three priorities for people with developmental disabilities in the next 3 years?

Question Four: (added after group 2) Now that you have decided the priorities, how should the money follow the person?

Question Five: What does the phrase individual directed supports mean to you?

Question Six: What are the training or technical assistance needs to implement this system throughout all of DDA? What do providers, people in services, DDA staff, families, resource coordinators, and others need to know or learn?

Question Seven: How do we align state regulations and systems to promote individual directed services?

Question Eight: Is there anything else you want to put on the table? Are there other ideas you would like to share?

Question One: What has been successful for people with disabilities in Maryland to this point? What worked?

# of respondents	Response
98	Individualized Supports and self-directed funding
75	Community services and innovative waiver
64	Closing institutions and moving people to the community
57	Family Support
47	Transitioning Youth Initiative
41	Supported Employment
34	Rolling Access
27	Waiting List Initiative
18	Residential
11	Quality and Ask Me
11	Service and Resource Coordination
10	Advocacy
6	Public Education
6	Technology
5	Creation of Department of Disability
5	Funding of Day Programs
4	Wage Enhancement for Staff
4	Eligibility Issues
4	Improved physical accessibility
3	Funding Intensive Behaviors

Question Two: What is not working in Maryland for people with disabilities? What are the barriers? What is missing?

132	Lack of Funding
80	Staff Training and Personnel
45	Lack of Transportation
42	No funding for the waiting list
37	Lack of Employment Options
33	Over regulation
23	Lack of Flexible Funding
22	Lack of Housing
20	Community Resistance
17	Lack of Behavioral Supports
13	Lack of Partnerships
12	Lack of Awareness by Families and the system is too complicated
10	Lack of services for adults with autism
9	Lack of Consistency
7	Lack of health care
7	Too Many Facility Based Models
6	Matrix
5	Lack of COLA
5	Lack of Customer Service by DDA staff
5	Need for Residential Facilities
4	Lack of Political Will

Question Three: If you were the state DD Director for DDA, what would be the top three priorities for people with developmental disabilities in the next 3 years?

68	**Innovation in Funding and Individualized Budgets**
64	**Move people off the waiting list**
59	**Staff Training and Wages**
48	**Employment for People with Disabilities**
42	**Fewer Regulations, Better Accountability, Better Data and Streamline Process**
34	**Housing**
32	**Fund Transitioning Youth**
30	**Better Collaboration and Partnerships**
27	**Fund COLA**
24	**No state institutions**
22	**Transportation**
14	**Fund Behavioral Supports**
14	**Fund Family Supports**
13	**Better Public Relations about the needs of people with DD**
9	**Health Care**
8	**Clearer Eligibility Standards**
6	**Address aging DD Issues**
6	**More Service Coordination**
4	**Provider Accountability**

The remaining questions from the focus groups contained lots of rich input but does not lend itself to a summary of the data. The full responses are being included for the remaining questions.

Question Four: (added after group 2) Now that you have decided the priorities, how should the money follow the person?

Funding based on Individual Needs

Funding based on individual needs

Funds needs rather than wants

Redetermination of services

Fund needs rather than wants

Money should address needs of individual

The money should be available to the person for as long as they have a disability and should be used for the welfare of the person to live a comfortable life, based on the needs.

Funds needs rather than wants

Funding should be based on assessed needs not wants and increase the use of natural supports

Prioritize

Funding should go to pay for whatever the need is

As independence increases, funding should decrease based on need

Funding determined by collaboration decisions among the individual, family, provider, case manager, and other stake holders

Less reliance on fitting into program and more reliance on fitting programs to the person

Balance person’s choices with fiscal security of provider agencies

Something like New Directions: An agency keeps tabs on what is spent but the individual has control

The person chooses with supports.

Based upon financial eligibility

Based upon fiscal case management with local and state supervision and guidance

Fund the person or family

Fund the person or family directly

Person directs the services

Allow for flexibility directly to consumer or family through professionals or vendors

Money follows the person with flexibility, allows for changing needs as people expand their opportunities

Money follows the person through independent choice and could go through a provider, family or broker

Team based decisions with a list of services available with an upper limit

Add as new component to the annul team meeting, based on individuals needs, linked to the budget

Team directs money

Team approach to how to use state dollars

DDA provides per capita funding to care management entities. Consumer centered teams will convene to discuss most appropriate supports. Use system of care principles. Distribute in an individual level.

Family allowed to select services from a cafeteria menu plan from the provider

The money goes to a provider or broker, based upon individual choice

Choice of broker or provider agency

Consultants

A well trained group of consultants is available to individuals to explore options.

Give money to the agency that would work with the individuals to broker services and provide needed fiscal and resource management.

Fund based on needs, allow funding to change as needs change

Pilot a voucher system, learn from the experience

Build in assurances to protect against inadequate services and funding irresponsibility

Develop a user friendly model to support the individuals in a more flexible way.

Budget allocated based on needs

Criteria for funding through use of a fair evaluation system.

Review spending quarterly rather than at the annual meeting

A safety net risk pool is established for emergency situations

Let money shift from one state to another state of you have the waiver program

DDA, MH, and DSS team follows and monitors the client

Have an assessment tool like MAPS to determine appropriate choice making skills for individuals to direct funds

Money follows the individual as their fiscal and self-advocacy skills grow, input could fade from the team

New training with centralized training for all providers and education for individuals and families

No “cap” on budget/ services

Establish clear flow of the money before hand. I.e. Guidelines/ expectations in accordance with CMS

Identify resources currently spent on individuals

ID money with individual Social Security #

Support with money, development of plan based on amount of money

Distribute funds to appropriate fiscal entity

6 month, then annual monitoring of how money is spent and who is responsible for training, hiring, etc

Let individual put anything on want list- amount of money will control choices

Redesign matrix system so people with most needs receive most funds

Expand definition of add on units to include inactive service needs

Apply for more waivers

We like the vouch if it stays out of SSA

We like the voucher idea

Develop a voucher system that would allow a person to determine purchase of services. Money would be based on needs. Have the ability to shop around, but limit some of switching

A Person Centered Plan and budget driven by the individual, but individual would have fiscal management agency paying the bills on person's behalf.

Couldn't work with CMS/ state to address reality issues/ expenses with needed accountability associated with use of public funds

The funding source would be universal and the individual would be able to create person centered Plan and as the individual needs change the funding will allow them with oversight by a creditable outside agency

Set up individual (or custodial) accounts for each person (like SSI) with automatic monthly payments and case worker follow up and verification of how used

Assign guardian or individual if capable (not to impact SS money)

Go to the parent/guardian if individual can't do

Assign budget monitor working in cooperation with team

Create unit of service categories tied to flexible budget

Funding can be terminated/ moved from service to service

Each fiscal year, person's fiscal requirements identified some flexibility in funding availability for changes in that year

All services are available as a cafeteria plan

All budgets are processed like the New Directions Waiver

Customer funding sources self-control- like voucher for speech therapy

Direct or to consumer or with control use service it

Create an economy where the money (tokens) only works for necessities. The remainder can cash out and follow individual

Somehow find a way for the same agency to handle the needs of people who don't know what their own needs are, along with the needs of people who do know what their own needs are

Money should be placed in the individuals personal bank account (with the help of the necessary individual) should be able to withdrawal funds as they need to use it.

Individuals should have their accounting staff to keep account of their funds

Identify the needs of the individual

The money would go to the individual no holding back

It would go directly to the person

All the money go to individual that are allotted

Money Follows the Person

Maximizing community integration in individual across the lifespan-including children with DD- money flows via account

Determine allotments for special needs and services. Assign allotted funds for implementation of determined needs and services. Award money id directly deposited in Individuals account and money handled by individual if possible or assigned to care giver or service provider and monitored for accountability semi-annually

Individual funds follow individual

Money should be provided to advocate to be placed in a checking account for which advocate must keep scrupulous records

Person has to keep track of money rep-payee system agency

They should write an outlook of needs. Put it in different categories (transportation, medical supplies etc.) different bank accounts should be made through DDA and have each category to have money places inside it- The log is maintained by DDA staff directly. Money is accessed on the need by need basis.

Person centered plan with rep payee- 40% health services 20% recreation and leisure 20% housing 20% vocational

Each individual is allotted an amount of money for specifies services. Individual chooses someone to allocate for services- advocate or individual tracks spending and outcomes

Provide a credit card/ vouchers for people with DD to purchase/ charge services

Apply for DDA funding like social security and SSI and then get money

Either person or committed family member or case manager has a purchasing card – amount determined by DDA- people or companied sign up to be eligible for card

Individual services grant funding: accounts based on need, income level of care/disability etc. – via through advocate, rep- payee or checking/debit card account

Develop budget when individual is young and alter it to meet the needs as they get older

Increase regional staff to oversee adequate process for eligibility and oversight of budgets for individuals as opposed to provider based budgets

Individual budgets based on person centered plan and monitored by regional offices

Lifetime budgets that are easier (less red tape) to increase/ decrease as needs change. More flexible, more usage options

Invest money interest bearing account- provide ATM card to access money

Supports are based on what a person wants/ is interested in and not just based on needs or what assessment says

Person served should have a menu of options available with associated costs. Would be able to change self-elections as needs change. This would assume all effective assessment and budget assigning process or person could enroll in all direction

Difficult to answer- new Directions, but this isn't going to work for everyone, Transitional supports need to exist- funded properly but accountable

Provide agency of amount of person's budget with adjustment for where they live (region)

Building community capacity for resources

Training Attorney (lawyers)

Funding person centered (with family input) but agency providing services- multiple agencies co-operating to fill needs

Allow individuals to purchase the service they need from agencies or individuals

Allow individuals the flexibility to purchase different services as needs change

Money from regional DDA to family agency with built-in oversights to prevent fraud. Both options must be available because some families/ individuals aren't able or willing to manage services

Options individual/families and also agency services (accountability)

Pay directly to family- eliminate the middle man that takes a %- audit expense and quality quarterly of bi-annually meets the persons needs

Person with disabilities or guardian- if no guardian possibly self- or appointed rep)

Different plan for different disabilities- more direct control to adult clients without cognitive and emotional challenges- spokesperson appointed for those with cognitive or emotional challenges (should be a care giver)

Individual identify what services are needed- i.e.- day, SEP, competitive emp, Res, CSLA etc.- choose who want- i.e. job coach or staff, own apartment once identified determine cost. Budget is written given to family to ok money is relaxed ok by DDA

Money goes to individual- individual shops for agency to buy services from

Money goes to agency but individual has independent account and decides where money is spent

Money directly to family, but receipts, accountability (similar to SSI) for how money was spent- % for different uses – separate check to insure adult needs met

Person or guardian established initial service matrix is consistent money to provider until person changes it

Choice from menu options in how money flow to individual from all money to agency- full support to individual total central- but a consistent system of accountability to ensure quality

Menu of options based on circle of support

Allocate funding to a 3rd party vendor. Allow them flexibility with line items within budget to ensure self- directed services allow for personal accountability (jointly with vender) federal money and state money to vendor. Vendor (well trained) will develop a PCP w/ assistance of outside resources (housing, friends). Then specific persons will be held accountable for each line item with in person’s budget (shared responsibility)

Through options based on the persons circle to support individualized services i.e. to person-micro board fiscal pass through

Increase regional staff (may need more financial staff) to ensure and review appropriate budgets for individual distribute for individual providers

Thru DDA not immediately- process to allow the decisions to be made

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Question Five: What does the phrase individual directed supports mean to you?

Getting what you need

We ask what you want rather than show you what we have

Ambiguous

Directed by whom: Is it clear?

Self-directed, family directed, care provided directed, budget directed, needs directed, regulation directed: What is it?

Need and personally directed

Spread the money out based on need

Take services out of group home thinking

Everyone needs and abilities are different

Individual has power

Individual has knowledge about choice.

People around the individual hears that perspective

We listen to people with DD

Person has the tools they need to communicate such as assistive technology, advocacy, mentoring

Implement and support

Help the person take action

Understanding of risk

Dignity of risk

Partnerships

Preference before perception

Based on individual needs

You don’t have to pick from a list of services

Customized services

Guided to make informed choices

Services identified by the individual, team and advocate

The individual purchases services from whomever

Person takes charge and directs

Choice

A Quality of Life, not just a life

Risk

Shared control

Respect for the person and their capabilities

Empowerment

Increase responsibility

Real goals

Meaningful to the person, like recreational services

Control

Diff person to person

Adequate to meet the needs on Individual

Self-directed

Personal choice

Changeable

Dignified

Creative perception of Individual

Listening

Individual right to say what they want

What one has not based on ability but based on wants

Money spent more effectively

Persons choose how to spend money, do not pick pre-approved list

Flexibility and freedom

Control

Eliminate functional labels

Greater opportunity

Empowerment

Choice

Options

Client says what service they want and they get to pick from options

Informed choices

Information available about potential supports

Options are known

Reality base: with context of need and take into consideration what others can fund or provide

Supports determined based on that individuals needs

Question Six: What are the training or technical assistance needs to implement this system throughout all of DDA? What do providers, people in services, DDA staff, families, resource coordinators, and others need to know or learn?

DSP: Training on administration of medication

Train DSP’s on self-determination, making choices, risk management

Start with direct line staff to understand individualized planning

Train police and medical professionals about contact with people with disabilities, especially the hearing impaired

Everyone should get training on respectful communication, especially people who don’t use their voice to communicate.

Doctors in emergency rooms need training

It is hard to write a service funding plan in 40 minute meeting, need flexibility to change the plan as you understand individual needs

Train staff to better work with people with DD who don’t verbally communicate.

How to manage staff training, resource allocation, staffing schedules. Use a coach model for organizational change.

Define different disabilities/ one size does not fit all. Define levels of support, medical needs, etc.

The community needs to be involved

New staff should experience how disability feels

Any staff in human services would know basic information to guide people with DD to services.

Look at the WISE system in Washington State

Training should include the individual, family, staff and school

Training for caregivers

Get input from dsp’s on what training they need

Cultural competency for staff on American values

Training and partnership across state agencies

Partner with state housing agency

Create an individual plan that looks at their whole life

Train all on informed choice

More in depth person centered planning

Educate the team

Everyone should use the same tool and plan

Technical assistance on SSI, SSDI, and Medicaid: how to use it with DDA funds

Better assessment of individuals, better tools

Train providers on meeting individual needs

People learned how to manipulate assessment tools to get better funding

Training on system accountability on how money is spent statewide

Create a tracking system for individuals on demographics, progress on goals, funding. All the information on all individuals would be in one place.

Create an on line ISP for everyone

Train DSP's on individual services, self-determination and dignity of risk

Have an adequate number of resource coordinators, with a single point of entry and make sure they get ongoing training

Train individuals with DD how to hire fire and retain staff

Create a library or central network with samples of supports

Special training for DSP's so they can help individuals attain their goals

Cliff notes on individual choices, options available, and define level of support

Strong linking with how to training for implementation

Co-hort consultants available for technical assistance

Ombudsperson for the process

Guides to help individuals understand the process

Guides on free services available

Information on recruitment and retention for employers hiring pwd

General accounting and book keeping skills for individuals or persons handling the money

Ongoing train the trainer model for staff working with individuals, keep thinking outside the box.

Training on conceptual change, for all involved

Help people with disabilities to be exposed to possibility.

On-line training for people supporting people in the community, provide credit like CEU.

Tutorial help window with frequently asked questions.

Technical assistance to families to help individuals decide goals in the spirit of collaboration

Technical assistance to DND to choices manage resources

Technical assistance to how to support persons with severe disabilities to make choices and self direction

Technical assistance on developing circle of supports

Help individuals with developmental disabilities find a champion to support them

Train provider staff on a new way of allocation of funds, who’s the boss, etc.

Technical assistance on building community connections

System of appeal if do not agree with DDA decisions besides State Legislature

Board of Nursing- application of medical model to people with disabilities

Everyone needs ongoing training- Government, community as a whole, legislature

Students with DD need to learn self-advocacy in school – move from compliances model

Families need to be educated in options- in collaborated with DDA and schools

Career planning for persons with DD- employment

Persons with disabilities needs education and training on non-traditional sources of funding

State needs training on how to protect people with disabilities

3rd party rating system- outcomes and services

Understanding of service options

Ability to make informed choices individual or their representative

Someone with knowledge of finance and law

Variety of resources in variety of formats so understandable and accessible to all

Community of practice form to exchange info on success

Personnel trained to understand variety of disabilities and their support needs

Ability to ask someone about their needs and wants as well as options available

Directory of funding options- SSI, housing, food stamps

Guideline steps to access

Family- timelines developmentally and how to prioritize

Community involvement

Concise description of services and funding options

Understanding of connecting people to community resources

Have Angie’s list- specific and generic

Question Seven: How do we align state regulations and systems to promote individual directed services?

If there are rules about services they need to be in writing and publically available on the Internet in a searchable data base.

Rewrite the spend down rules on an individual basis.

Training rules are often a need jerk reaction. Regulations should be reviewed and revised.

Too much emphasis and money spent on planning shift the focus to implementation.

Self-direction seems to be all or nothing. No way to sue traditionally providers to help provide supports.

Residential participants should have a choice to go to day program all day or to have flexible options.

Look to model after SSI allocation of funds.

There should be individuals driven budgets with annual self audit and accountability and oversight.

People need to be able to access non-conventional services.

Don't go to a medical model.

Push back the board of nursing so individual needs are met.

Understand conflict within existing regulations and get alignment

Do not use regulations as barriers

Don't need new regulations: modify existing regulations

Find out which regulations focus on process and paper: change them to focus on outcomes

Regulations are not objectively interpreted

There needs to be creativity in regulations

There should be one regulation and that should be the ISP

There are other regulations from other state agencies that conflict

Change BON

Eligibility and access regulations need to be more consistent

Look at other regulations for opportunities

No new unfunded mandates from regulations.

Change regulations if you own your own home. You should not have to lock up your medications if you own your own home

Change the BON regulations on self-administration of medications, storing, giving and getting medication. They are too restrictive

Change the regulations on PRN medications. You should not need a doctor's order for sun screen.

All regulations should be reviewed to determine if they are necessary and to check if they protect individual dignity.

New Directions: not clear what you can't and can do with the money, Need more clarity

Need better universal guidelines for Rolling Access, 3 people give you a different answer from the same provider agency

Lack of rules would allow things to be more flexible

Direction vs. flexible, we need balance

Borrow ideas from other states

Pilot, evaluate, modify

Look at Title 7, change limits on respite, waive regulations based upon the individual

Look at all the regulations regularly to see if they are still relevant

Regulations are purposefully vague, but the interpretation is subjective

Research difference between real rules and past practice

70 not the break off I.Q. in Maryland

Training requirements in regulation do not reflect the need of staff and are firmly dictated

Clarify regulations/ clarify interpretation of regulations

Look at other state agencies regs to make sure they fit ISS

Regulations- simple, use common sense, language all can understand

Most regulations- illness based move to wellness model, stuck in public health model

Open communication with other agencies so individual supports equal success (3rdparty vendor, other state agencies, providers)

Certification or providers

Mechanisms to monitor staff- educate staff

Certification of staff- go state to state

Regs get in the way of individual supports (barriers to social connections)

One size does not fit all

Question Eight: Is there anything else you want to put on the table? Are there other ideas you would like to share?

Increase DDA budget for individual supports based on individual needs.

Check why my PA hours are cut: What are they doing with my funding?

Look at duplication of services.

Need to educate legislators.

Need to organize all stakeholders to advocate for increased funding.

DDA only comes to audit and criticize.

DDA staff needs to proactively be with people with DD and people with DD who have no services.

This forum is excellent.

People should not have to lose all their assets to get services.

Take care of caregivers, including parents.

Potential expending crisis list as parents age while child with DD in the home, need proactive solutions.

Solutions to serve people before crisis.

Need to structure partnership with DDA, providers, contractors, etc.

Lack of network.

Eliminate adversarial role DDA and providers, providers and families, and move to focus on the individuals.

People who are in crisis should not have to accept what is available. They should be able to identify what their service needs and preferences are, like still need near their family.

DDA staff need to understand non-traditional supports.

It was a little uncomfortable to discuss the specific region problems while the regional staff were in the room.

Celebrate

Cultivate self-advocacy

Celebrate individual good staff

People want to help do the right thing. DDA should assume that people want to do the right things, but they need help and training.

Form partnerships with providers.

Do not assume that people have bad intentions.

Rural areas have limited shopping, need to expand options.

Stop waiting, get ready sooner for students leaving school, and identify potential needs.

The system is so slow. It takes forever to get funding.

Need better information on status of individual budgets within DDA.

Resource coordinators and family need to understand the how the system works.

Define roles and responsibilities of resource coordinators

Change eligibility regulations, ISS, get rid of non-DD people getting DD services

Expand other waivers.

How do we include DD population in increased volunteer efforts?

Need direction on who should get priority funding, especially with respect to deinstitutionization and community

What do we do with DD people with more intensive needs?

What do we do as needs for people change?

DDA should work with the Office of Deaf and Hard of Hearing, Deaf Independent Association, DD Council to create a mechanism to provide supports for DD and hard of hearing in the least restrictive environment. Do not group people based upon disability.

Emphasis on DD who are aging and do not want to work, but still want meaningful days

How do you attract providers to support people with challenges like forensics?

How do we support people with disabilities who are parents?

How do we build in cost efficiencies?

Self-advocacy is a success, but 1st thing cut from the budget

Cross training so one part of government does complete audit

Lack of public awareness: lack of will to support DD

Excess level of Executive compensation to some local providers

Do not push fads- we need a broader perspective, need to remember all people with disabilities, one thing does not work for all- don’t leave people behind

DDA staff should be knowledgeable consistent and available and sensitive and be able to communicate clearly

Regions: should be consistent, but there are different issues in different areas

Geographic areas in MD have different resources. Need to examine if each ______has an adequate provider for specific needs and help develop providers/services in some areas of State

Planning around people who are aging needs to be part of strategy. People will lose parents and some will not be able to direct services alone

Why not focus groups in Montgomery County

Increase emphasis on recruiting and self-advocacy

Transitioning school to adult supports- night mare- needs to be streamlined

Services not just available to people who know how to call the State Senator

Need options for people with disabilities who fall through the cracks

Need agency that just explains things and options for supports

Make sure services are equitable and available statewide

Increased collaboration- schools & DDA, friendly and honest

Treat people with disabilities with respect especially staff

Tell community about our success

Get community in line with our vision

Promote success vs., horrors

People with disabilities tap into community resources

Increase supervision and regulations on funded employment agencies

Recognize and respect that people with disabilities are people first

Balance oversight with advocacy and need for privacy and opportunity to develop relationships

DDA work out something with transportation