

My Life, My Community!

Re-designing Supports for Virginians with Intellectual and Developmental Disabilities

Project Report

November 5, 2013

Project Tasks 1.3 & 1.4:

Public Forum and Interview Results



**Human Services
Research Institute**

My Life, My Community!

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Project Report

November 5, 2013

Project Tasks 1.3 & 1.4: Public Forum and Interview Results

Prepared for:



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This project is sponsored by the Virginia Department of Behavioral Health
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All opinions expressed herein are solely those of the authors and do not
reflect the position or policy of DBHDS.

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Introduction

The Human Services Research Institute is under contract to the Virginia Department of Behavioral Health and Developmental Services (DBHDS) to: (a) evaluate the state’s current service delivery system for individuals with intellectual and developmental disabilities (ID/DD); (b) make recommendations to move the system to a more person-focused/needs-based system of care and (c) in conjunction with that evaluation, review the existing rates paid to service providers and the current method of allocating resources to support individuals receiving services.

Tasks 1.3 and 1.4 in the first phase of this project required the conduct of interviews and public forums and the preparation of a report to describe methods and findings. To this end, staff of Parent to Parent of Virginia (PTPofVA) and the Partnership for People with Disabilities at Virginia Commonwealth University (Partnership) convened multiple open forums at eight sites across the state to offer the public opportunities to comment on the performance of the present HCBS waivers and solicit input on what could be done to improve system performance. HSRI staff played a support role for convening these forums, attending five of the eight. In addition, the Partnership worked with HSRI to coordinate 30 interviews of individuals representing various constituencies across the state.

The following provides a description of the: (a) methods applied to convene the forums and conduct the interviews, (b) findings resulting from these activities, (c) concluding remarks, and (d) appendices.

Methods

Forums

From a list of potential forum locations identified by PTPofVA, the Partnership, and HSRI, DBHDS selected sites across the state, covering both urban and less populated areas. The sites selected included:

Abingdon	Colonial Heights	Hampton	Manassas
Alexandria	Danville	Lynchburg,	Virginia Beach.

A flyer was developed to highlight the purpose of the forums, locations, and the availability of two time slots (see Appendix A). Flyers were distributed electronically by PTPofVA and Partnership staff to 25 partnering agencies, through four statewide listserves, and via posts on five Facebook accounts. In addition, PTPofVA contacted a number of local newspapers to request that the information be posted in the public notice section. Careful attention was made to selecting local sites that were low to no cost, open to the public, accessible, and could seat 75-100 people. Sites included hotels, libraries, community organizations, higher education centers and local schools.

In anticipation of 35-50 people attending each session, PTPofVA and the Partnership developed a process for conducting the forums that solicited input from all attendees and identified priority areas for DBHDS. The identified process sought to engage all attendees. Forums were staffed by PTPofVA, Partnership, and HSRI staff. The agenda of the forums included the following items:

- Welcome by PTPofVA (5 min)
- Overview of the *My Life, My Community* waiver redesign study (25 min)

- Hopes for the waiver in the future activity (10 min)
- Small group recording of attendee comments (50 min)
- Priority voting activity (20 min)

Following a short slideshow presentation of the *My Life, My Community* project, participants were asked to write down their hopes for waiver services in the future. Attendees were next asked to self-select into one of three topical area groups regarding the current service delivery system for individuals with (ID/DD). These topical areas included: Access and Planning, Service Delivery, and Cost/Rates/Funding.

These domains were consistent with domains included in the semi-structured interview protocol so that trends could be extrapolated from both methods of gathering stakeholder input. The main focus of the small group activity was to identify areas of the system that were working well for individuals and families using ID/DD services and identify changes that needed to be made to better meet the needs of stakeholders.

At the conclusion of the small group activity, each participant was given 9 dots (3 sets of dots labeled 1,2, and 3) and instructed to vote on their top 3 priorities for DBHDS in each of the discussed topical areas. The PowerPoint slide presentation shown to participants appears in Appendix B.

As highlighted in the table below, between September 23rd and October 10th, 967 people attended the forums. There were an additional 5-10 individuals at each session who did not sign the attendance form, bringing our estimated attendance at 16 sessions to 1,100. While unexpected attendance numbers in several sessions made space tight, comments from participants were overwhelmingly positive about the process and the opportunity provided to have input into the waiver redesign process.

Forum/Meeting Location	Date	# Attendees			
		Total Attendees	% Individuals	% Family Members	% Provider/Advocates
Abingdon	September 24 th	50	2%	30%	68%
Alexandria	October 10 th	128	12%	51%	37%
Colonial Heights	October 8 th	162	8%	29%	63%
Danville	September 23 rd	74	7%	25%	68%
Hampton	October 3 rd	110	19%	30%	51%
Lynchburg	September 25 th	118	9%	41%	50%
Manassas	October 9 th	191	17%	37%	46%
Norfolk	October 2 nd	134	14%	43%	43%

Interviews

Semi-structured interviews were also held with ID/DD system stakeholders to gather data on the operational parameters of the current HCBS waivers, to solicit information on local circumstances influencing waiver administration and implementation, and to seek recommendations on needed

system enhancements. Thirty interviews were conducted by HSRI and Partnership staff with individuals with disabilities, family members, advocates, provider agency representatives, Administration on Intellectual and Developmental Disabilities (AIDD) partner agencies, university-based experts and government leadership/policymakers. Interview questions were organized around the domains of overall direction, access and planning, service delivery, rates and other. Interviews ranged in duration from 1 to 1 ½ hours. The interview protocol and questions developed by HSRI are included in Appendix C.

Summary Findings

The purpose of this report is to provide an account of feedback gathered through the two methodologies. A list of specific comments collected during the forums and outside the forums related to waiver structure, implementation, and needed services to better support individuals and families are in Appendix D and Appendix E, respectively.

Listed below are overall recommendations for guiding future policy actions to improve the ID/DD system. When reviewing these recommendations, understand that Virginians were not always in agreement on all matters. For instance, while most wanted a unified response to people with intellectual or developmental disabilities, some preferred that DBHDS maintain separate waivers keyed to diagnostic classification. While most signaled that the state should focus on a community centered system, a few others lamented the closing of Training Centers. While many urged a de-emphasis of the role Community Service Boards play, others suggested that the role be expanded.

Contrasts in opinion like these were not uncommon across a range of issues, though great consensus could be found on other topics. For example, uniformly participants observed that service reimbursement rates need to be increased, that the service array needs to be broadened to promote community oriented support, or that the state should do more to support families.

Still, amid the thousands of individual observations and opinions that were expressed, particular themes emerge that focus on a few particular recommendations. These four primary recommendations, shown below, are organized around a single guiding principle:

Primary Principle: One Unified Needs-Based Waiver

Forum and interview participants want a streamlined, needs based waiver in Virginia that offers an all-inclusive menu of service options that are based on individual needs. This waiver should be administered in a uniform way across the state and must be transparent to the individuals and families who use services and supports. General guidelines for waiver reforms are as follows.

1. The waiver needs to address the increasing demand for services in the state.

Participants felt that individuals who meet the eligibility criteria should not have to wait for waiver services. If the new waiver does have a waiting list, participants indicated that they want fairness, need, transparency, and uniform administration to govern the waiting list prioritization. For those who cannot access waiver services, a support system should be in place so one does not have to be in crisis to get their needs met.

2. The waiver should offer a flexible array of services that allow for choice, control, and creativity to meet individual needs and preferences.

Increased choice and control in waiver services were major priorities in both the forums and interviews. Individuals and families are very interested in individual budget authority in waiver services. There is a perceived lack of transparency in how waiver funding is used to purchase services. Many individuals and families feel that they cannot choose specifically what services they need and they report that they are offered bundled, more congregate services. The community service system also needs to be robust enough to address the needs of all individuals, including those with complex medical and significant behavioral health needs.

3. Waiver rates need to be commensurate with the costs of providing services.

Participants stated that rates should be based on service costs and sufficient to meet the demand for more creative, individualized, person-centered services. Current rates are an impediment to attracting and retaining quality service providers in all areas including small residential settings, behavioral support, skilled nursing, employment, transportation, and occupational, speech, and physical therapy. Additionally, rates for direct service professionals are not sufficient to attract and retain a sufficient number of qualified staff.

4. The waiver needs a uniformly implemented, sound infrastructure for screening, determining eligibility, providing case management/service coordination services that enables users to access services free of conflicts of interest.

The vast majority of interview and forum participants felt that there should be a single point of entry for all people who use waiver services. Through this point, individuals and families should have easy access to comprehensive, reliable, accessible information in multiple formats on available services and supports. Screening and eligibility for waiver services should be determined using uniformly administered, accurate instruments. Many participants also communicated that case management services should be decoupled from service provision agencies because of the inherent conflict of interest that presents. As case management or service coordination is fundamental to the successful navigation of waiver services, participants stated that a comprehensive training and quality management system needs to be in place to better monitor implementation and reinforce quality standards across the state.

Concluding Remarks

A wealth of information was gathered through stakeholder forums and interviews. The overwhelming participation rate in both efforts is a testament to the interest in ID/DD system reform and the commitment of stakeholders to engage in crafting a vision for the future. Stakeholders communicated a keen interest in continued involvement in the system reform process and provided many specific suggestions for changes in the waiver's structure and implementation. Please see Appendix D for a full listing of forum comments and Appendix E for a full listing of comments collected through an email address provided by DBHDS after the public forums.

APPENDICES

Appendix A: Forum Flyer

My Life, My Community

Re-designing Supports for Virginians with Intellectual and Developmental Disabilities

DBHDS
Virginia Department of
Behavioral Health and
Developmental Services

Where & When

Danville

September 23, 2013
Danville Institute for
Advanced Learning and
Research
150 Slayton Avenue

Abingdon

September 24, 2013
SW Virginia Higher
Education Center
One Partnership Circle

Lynchburg

September 25, 2013
Lynchburg Public Library
2315 Memorial Avenue

Norfolk

October 1, 2013
Independence Center
6300 E. Virginia Beach Blvd.

Hampton

October 2, 2013
Crowne Plaza Hotel Hampton
700 Settlers Landing Road

Colonial Heights

October 8, 2013
American Legion, Post 284
505 Springdale Avenue

Manassas

October 9, 2013
Holiday Inn
Manassas Battlefield
10424 Balls Ford Road

Alexandria

October 10, 2013
West Potomac High School
Room 507
6500 Quander Road

**Two sessions will be held
in each location:**

3:00 – 5:00 p.m.

6:00 – 8:00 p.m.

(An additional breakout session for
people with I/DD will also be held
during the 6-8 pm meeting)

Light refreshments will be
served.

Public Meeting

We want to hear from you! The Virginia Department of Behavioral Health and Developmental Services is making changes to the service system for people with developmental and intellectual disabilities.

Changes are being made to improve the service system and help the people who receive services to live and participate in their communities. Many of these changes will focus on Virginia's Home and Community Based Services Waiver programs. To provide input on the changes needed, we want to know what you are thinking!

Virginia is hosting 16 meetings in eight sites across the state. We hope you will attend one of the meetings. At each site there are two session times. Each session will include a short presentation about the anticipated changes to the system and discussion. The evening session will also include one breakout session designed especially for people with I/DD. There is no registration required to attend the meetings.

Sign language or Spanish interpreters are available but you must let us know if you need either service a **minimum of 72 hours** before the meeting.

Who Should Attend

- ◆ People with Disabilities
- ◆ Family Members and Friends
- ◆ Advocates
- ◆ Service and Support Providers
- ◆ Case Managers/
Support Coordinators
- ◆ Direct Support Professionals
- ◆ Employers
- ◆ Concerned Citizens



Questions?

Email: PTPofVA@aol.com

Call: (804) 828-0352

Appendix B: Forum PowerPoint Presentation



My Life, My Community
*Re-designing Supports for Virginians with
Intellectual and Developmental Disabilities*

Project Description

Virginia Department of Behavioral Health & Developmental Services

Slide 1

2

AGENDA

- Quick Overview of My Life, My Community Project
- Your Hopes Exercise
- Small Group Activity
- Voting on Priorities

My Life, My Community

Slide 2

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Project Leadership

State Administrative Leadership Team

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Slide 3

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Systems Re-design Project Overview

- Overall Goal
- Some Context
- Three Basic Intentions
- Project Partners
- Project Tasks

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Slide 4

Overall Goal

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The Department of Behavioral Health and Developmental Services (DBHDS) wants to improve the system of supports so that people with intellectual and developmental disabilities have the supports they need to live full lives in the community.



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Some Context

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DBHDS is faced with several challenges including:

- The Department of Justice settlement agreement, which states that DBHDS must:
 - Serve an additional 4,170 people in the State's community based services (HCBS) waivers in the next 10 years (This is a 40% increase);
 - Create a statewide behavioral crisis system;
 - Develop community living options to allow individuals to live independently in the community or in settings with four or less residents;
 - Provide integrated day opportunities that include supported employment;
 - Make improvement to the quality and risk management systems; and
 - Transition over 800 individuals to the community.
- Increasing wait lists for the Home and Community Based Services (HCBS) waivers;
- General agreement that the current waivers do not include services that fully support people with ID/DD in their local communities.

The challenges faced by DBHDS are daunting, but also provide a tremendous opportunity to reform the service delivery system

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Three Intentions of the Project

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The three basic intentions of this project are to:

- Evaluate the State's current service system for individuals with intellectual and developmental disabilities (ID/DD);
- Make recommendations to move the system to a "more person-focused/needs-based system of care;" and
- Review the existing rates paid to service providers and the current method of allocating resources to support individuals receiving services.

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Project Contractors and Partners

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In July 2013, DBHDS contracted with the Human Services Research Institute and its partners to complete project tasks over 12 months. Partners include:

- Burns & Associates
- National Association of State Directors of Developmental Disabilities Services
- Parent to Parent of Virginia
- Virginia Commonwealth University—Partnership for People with Disabilities

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Project Tasks

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The Project is divided into two phases.

DBHDS expects that it will take 12 months to complete the work.

Phase

1

Phase 1 focuses on reviewing the current HCBS waivers for people with intellectual and other developmental disabilities and reaching an agreement about how they might be changed.

Phase

2

Phase 2 focuses on building an assessment-based resource allocation model using the Supports Intensity Scale (SIS) and a complementary provider rateschedule.

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Phase 1 Tasks

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Phase 1 focuses on taking a look at the current HCBS waivers for people with intellectual and other developmental disabilities and reaching an agreement about how they might be changed. This will include:

- Looking at service definitions, billing rates, documentation requirements, and various DBHDS policies;
- Conducting **Public Forums** around the state to see what people think about the waivers and what should be done to change them;
- Discussion among state leaders to decide what to do going forward; and
- Supporting actions taken by state leaders to alter HCBS waivers approved by the federal government.

Phase

1

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Phase 2 Tasks

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Phase 2 focuses on exploring an assessment-based resource allocation model using the Supports Intensity Scale (SIS) and a complementary provider rate schedule. This will include:

- Developing and implementing a plan for communicating with stakeholders;
- Analysis of information collected on support needs of individuals;
- Completion of a cost study to revise service reimbursement rates;
- Developing two options for allocating resources to individuals;
- Understanding what other changes to the system need to be made; and
- Finalizing a plan for implementing a new system of services.

Phase

2

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12 Public Forums

Forums are being held in 8 sites across the state for the general public including self-advocates, family members, providers and others to:

- Provide an overview of the project
- Gather input from stakeholders



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Now we want to hear from you!

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Forum discussion will include the following topics:

- How do you feel about the current system?
- What could be done to improve the quality of services?
- How do you feel about the service options that are available?
- How do you feel about the current rates for services?



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AGENDA

- Quick Overview of My Life, My Community Project
- Your Hopes exercise**
- Small group activity
- Voting on priorities

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Your Hopes Exercise

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- Take 5 minutes to consider and answer the following question on the white paper provided:

**What are your hopes for Waiver services
in the future?**

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AGENDA

- Quick Overview of My Life, My Community Project
- Your Hopes exercise
- Small group activity**
- Voting on priorities

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Small Group Activity

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- In small groups, review the topical questions at your table for:

Access and Planning Service Delivery Cost, Rates and Funding

- For the topic at your table, think about what Virginia should **continue** to do in its Waivers and what it should **change** in its Waivers

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Access and Planning

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What should be CONTINUED or CHANGED about:

- How people learn about waivers and apply for services?
- How people are found eligible for services?
- How the wait list is handled?
- How case management and service coordination are managed in Virginia?
- How planning for services and supports are carried out?

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Service Delivery

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What should be CONTINUED or CHANGED about:

- The types of services/supports offered through Virginia's waivers?

- Crisis and behavioral support services?

- Services that offer more self-direction such as consumer directed services?

- Services offered to individuals who live with their family?

- Services for individuals who need intensive medical support?

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Costs, Rates and Funding

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What should be CONTINUED or CHANGED about:

- The funding for services in VA's waivers?

- The cost effectiveness of the services in the waivers?

- How individuals can understand and direct the funds that are being spent on their services?

- How the rates affect the quality of the services people receive?

- Promoting quality and cost Effectiveness of services?

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Small Group Activity

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- Using the pink, blue or green colored paper provided, take 10 minutes to write down 2 to 4 thoughts, issues, comments on what should continue and what should change about the topic at your table

- A facilitator (in a 30 minute period) will go round robin at each table to record on chart paper what each of you has to say

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AGENDA

- Quick overview of My Life, My Community Project
- Your Hopes exercise
- Small group activity
- Voting on priorities**

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Voting on Priorities

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- Facilitators at each table will take 3-5 minutes to summarize and report out to large group what was discussed
- You will each receive stickers numbered **1 2 3**
- You will walk/roll around room to each chart and vote 3 times on what you believe are the top 3 priorities related to:
 - Access and Planning
 - Service Delivery
 - Cost, Rates and Funding

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Other thoughts, ideas, comments...

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- If you have other comments, please write them down on the large sticky notes near the door and post them on the wall chart.

MyLifeMyCommunity@dbhds.virginia.gov



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Appendix C: Interview Protocol and Questions

The Human Services Research Institute and the Virginia Department of Behavioral Health and Developmental Services (DBHDS) are engaged in a two phase project entitled “*Virginia’s System Transformation for Individuals with Intellectual Disability/Developmental Disability (ID/DD).*” This effort is focused on building on work to improve the system to achieve a comprehensive review, analysis and enhancement of DBHDS’ Medicaid HCBS waiver programs for people with ID/DD. Phase One focuses on taking a look at the current HCBS waivers for people with intellectual and other developmental disabilities and reaching an agreement about how they might be changed. Phase Two focuses on exploring an assessment-based resource allocation model using the Supports Intensity Scale (SIS) and a complementary provider rate schedule.

Our activities are designed to address: the day-to-day challenges faced by individuals with ID/DD and family members and those responsible for responding to their needs, and recommending reforms and new practices that DBHDS may institute to establish an enhanced service system.

To complete the scope of work, we will:

- Conduct research of past work with the HCBS waiver design, conduct an analysis of claims data by service to understand the variance in service utilization and expenditures across the state,
- Speak with individuals and organizations to learn about the present system including the operational parameters of the current HCBS waivers and to take stock of local circumstances and advise us of what must be done to enhance the system.
- Develop recommendations to guide policy actions over time to improve performance and align day-to-day practice with the stated vision.

During Phase One, the HSRI project team will look at service definitions, billing rates, documentation requirements, and various DBHDS policies; conduct public forums around the state to see what people think about the waivers and what should be done to change them; talk to state leaders to decide what to do going forward; and support actions taken by state leaders to alter HCBS waivers approved by the federal government.

Virginia Department of Behavioral Health and Developmental Services

MISSION

We provide leadership and service to improve Virginia’s system of quality treatment, habilitation, and prevention services for individuals and their families whose lives are affected by behavioral health disorders or developmental disabilities. We seek to promote dignity, choice, recovery, and the highest possible level of participation in work, relationships, and all aspects of community life for these individuals

Direction

- What is your perception of the current service system for individuals with intellectual and other developmental disabilities in Virginia? Would you say that generally things are going well, or off track?
- What do you feel are the greatest challenges?

- How do you think combining the developmental and intellectual services will affect you and the services you receive?

Access and Planning

- From the time they are deemed eligible, do individuals with I/DD receive services with reasonable promptness (within 60-90 days)?
- In your opinion, how do individuals get off the wait list? Does the process differ from waiver to waiver? If so, how?
- How would you describe the quality and effect of the case management services people receive? What might be done to improve case management services?
- How would you describe the service planning process? Would you characterize them as “person-centered” generally? What might be done to improve the planning process?

Service Delivery

- Does the current system of services and supports align with the vision and direction that has been set?
- Are you satisfied with the current service array? If not, what are you unsatisfied with? What services should be added or eliminated?
- What service or funding trends do you see in play? (e.g., increases or decreases in individuals receiving supports living at home, residential options, emphasis on employment)
- From your perspective, are the current crisis and behavioral support services available in Virginia adequate? What might be done to improve the response?
- In Virginia there are several different waiver options. Are there differences in service options among these waivers in the following areas?
 - Options for people to live in the most integrated setting
 - Self-directed service options
 - Support for families who have members with I/DD living at home
 - Opportunities for individuals with IDD to get regular jobs
 - Services are provided in a cost effective way
 - Services are consistent with the expectations of people with I/DD, family members, providers and others

Rates

- Are you satisfied with the current level of financing for the system?
- Does the current rate structure adequately support the service array?
- Are there particular services where you think that the rate is too high or too low?

Other

- What other concerns or opinions that you want to share?

Appendix D: Forum Comments

Location: Abingdon
Session: 3:00 – 5:00 p.m. Sept. 24, 2013

HOPES FOR FUTURE OF WAIVERS

- More slots, quicker approvals, nursing rates increased
- More slots, better rates, dental care, one on one staff who specialize in behavioral issues.
- More service facilities, more programs available for waiver, agency directed services, look at new functional assessment.
- More slots
- The Commonwealth will develop a system that can provide needed services through a reasonable rate structure
- Better rates, more slots.
- DD waiver will become more organized; DD waiver will include residential services, more ID waiver slots, intensity-based reimbursement for providers.
- Waiver services to be more locally governed – states being able to alter waivers as needed.
- Available to people who function highly but have needs for services to stay in the community.
- Follow throughout lifespan.
- Wait list to zero.
- More waiver slots in far Southwest.
- Equal access to available and most pertinent services for all persons with ID/DD.
- Hopefully waiver services will have respite (agency directed) services.
- I want the training centers to stay open.
- To be available for all that want the service in the area of service that is needed.
- The waiting list for waivers would disappear.
- More slots (ID), increase in the rates for services, additional service coverage, dental, etc.
- Services will be expanded to eliminate waiting lists.
- I hope group homes remain an option for individuals. There seems a push to move from this kind of residential setting.
- No more or less waiting.
- Less waiting time for approval.
- More tailored to actual support needs of individuals with a sensible rate attached to the services.

TOPIC: Access and Planning

Access & Planning Comments	1st	2nd	3rd	TTL
Continue services for people with ID				
Provide more awareness of services that are available				
Make services easy to access	3	3	2	8
People don't know providers unless you are in CSB				
Be consistent in eligibility screening (parents income does not count)				
Pay for special educations services				
Provide education on waivers to teachers and school personnel		2	1	3
Provide training to whole community (physicians, hospitals, parks/rec, police, etc.)				
Make process for applying simpler for families				
Have more consistency in funding menu	1	2		3
Increase tailoring of services to individual	1	1	1	3
More people to do testing (IQ?)			1	1
Fund psychologicals, neuropsychologicals		1		1
Set individual budgets, money goes directly to individual				
Fund more slots	4	4	4	12
Have consistent case management, higher level of competency, consistent funding per CSB, consistent training, educational requirements		2	3	5
Broaden criteria to get waiver	1	3	4	8
Provide incentives to reward individual independence				
Reinstate and/or use grace periods				
ISARS cause people to sound needy as possible to qualify for payments		1		1
ISARS not user friendly, too much justification required		2	1	3
Pre-authorizations to do home visit				
Rate reimbursement tiered to be fair, needs to be attractive to pull in qualified providers	2	1	3	6
Provide more incentives in rural areas	9	2	1	12

TOPIC: Service Delivery

Service Delivery Comments	1st	2nd	3rd	TTL
Continue START crisis system for adults	4	1	2	7
Continue supported employment		3		3
Continue day support and pre-vocational services	2			2
Continue personal assistance services			1	1
Continue coverage for medical services				
Increase availability of group homes to provide respite services, particularly those leaving training centers		3	3	6
Increase waiver services for dual eligible (MH & I/DD)	10	3	2	15
Increase behavioral support services		2		2
Offer dental services to adults	2	2	2	6
Offer nutritional consultations				
Medical services shouldn't be dependent on providers to be covered		3	1	4
Offer 24 hour care				
Offer coverage for specialized equipment	1		2	3
Provide crisis intervention services for children	1		1	2
Increase residential facilities		1	1	2
Provide education to families to understand waiver services, rates, etc		1	2	3
Coverage for specialized, qualified staff				
Expand supported employment	4	1		5
Continue agency directed services	3	1	4	8
Expand respite services				
Increase specialized training for providers		4	7	11
Have a variety of providers in order to make a true informed decision/choice				
Improve transportation services and number of providers beyond logisticare				

Topic: Costs, Rates & Funding

Costs, Rates & Funding Comments	1st	2nd	3rd	TTL
Offer congregate (more than 4 bed) as an option		1		1
Keep environmental modifications and assistive technology rates				

Costs, Rates & Funding Comments	1st	2nd	3rd	TTL
Increase funding across the board for services	7	5	4	16
Reimburse for follow along case management				
Funding people who fall between the cracks	3		5	8
Increase accountability for consumer directed services	1	3	1	5
Define and change duties and responsibilities of services facilitators			1	1
Rates need to reflect true cost of services	11	5	1	17
Increase nursing rates		1	3	4
Implement rate differential based on support needs	4		1	5
Increase rates based on cost of living raises		2	2	4
Include staff training and retention in rate considerations		4	1	5
Pay compatible salaries for quality staff		1	2	3
Build in way to appeal rate that does not meet need			1	1
Restore respite hours to level before cut		4	5	9
Increase oversight of allowable assistive technology devices and environmental modifications		1		1

Location: Abingdon
Session: 6:00 – 8:00 p.m. Sept. 24, 2013

HOPES FOR FUTURE OF WAIVERS

- More respite and group homes in this area and also day services.
- We need more employees at our Center for Day Support.
- That everyone who is eligible for a waiver could have access to one.
- That the screening process were easier and reading accessible.
- Provide quality care and services for persons with special needs and improve on workers benefits and insurance.
- For all to be as independent as possible and enjoy life no matter what their disability.
- More life skills classes.
- All persons are served – no waiting list.

- I would like nothing more than to see a continuation of the wonderful services we receive for our son.
- Individualized supports and services.
- Made available to individuals in an easier manner.
- Rates will reflect the needs being provided for.
- Try to do away with waiting lists; more funding for staff; reduce work load on case managers and service coordinators; continue good programs that are working well for individual; clarify the appeal process; try to reduce the paperwork for providers.

TOPIC: Access and Planning

Access & Planning Comments	1st	2nd	3rd	TTL
Continue in home residential and day support services	3			3
Keep good programs that are working well				
Increase rates to meet needs of individuals	2	1		3
Provide group meetings in schools for parents			1	1
No wait list	5	3	1	9
Change Level of Functioning so more people are eligible	1		1	2
Educate case managers so they know all options				
Increase pay rate for staff	1	1	1	3
Reduce workload of case managers			1	1
Clarify appeal process				
Reduce paperwork		1		1
Change way timesheets are completed			1	1
Make benefits/insurance available to workers			4	4
Increase group homes	1	2		3
Reconsider the NOVA differential rate		1	1	2
Exempt wages from supported employment (so it doesn't affect SSI eligibility)		1		1

TOPIC: Service Delivery

Service Delivery Comments	1st	2nd	3rd	TTL
Continue array of services				
Continue day support				

Service Delivery Comments	1st	2nd	3rd	TTL
Consider residential options, group homes, for people with less intensive needs	1			1
Increase crisis services provided in the home		4		4
Increase provider pool of in-home behavioral supports	1			1
Need provider equity across counties	1	4		5
Cover therapeutic recreation as part of waiver services	3		1	4
Increase respite hours and flexibility of service	2	1	3	6
Increase rates so agencies can provide services, not just consumer-directed	1	1		2
Have flexibility to pick services needed	1		3	4
Provide ways self payers can access services			1	1
Let agencies accept self pay				
Increase providers of independent living, job supports				
	1		1	2

Topic: Costs, Rates & Funding

Costs, Rates & Funding Comments	1st	2nd	3rd	TTL
Have rates reflect a person's needs	4			4
Use care in using SIS for budgeting and planning		3	2	5
Equity in funding (some getting a lot, some getting nothing)	1		1	2
Increase funding for services		2	1	3
Examine funding to ensure funds are fairly distributed		2	2	2
Concerns about budget cuts impacting waiver services	2	2	1	5

Location: Alexandria

Session: 3:00 – 5:00 p.m. Oct. 10, 2013

HOPES FOR FUTURE OF WAIVERS

- Peace of mind that the joint ID/DD waiver will provide good residential care for my son if/when needed

- Commitment of money
- That they are accessible to all who need them
- Early assistance based on needs of family and individual
- Behavioral consultation expanded to include services
- That the ID/DD waivers will include dental services
- Services will be both broader and deeper reflective of the fact that many consumers are not getting services of the quality or quantity needed; that some services will “bloom” with more availability to competent behavioral services
- That there will be a secure funding source that doesn’t depend on whether legislators fund it
- Direct caregivers will have training to safely support individuals with severe behavioral challenges
- Rates equal costs
- More choices of providers’ services
- A single comprehensive waiver for people with ID and DD (including sensory disabilities, adult onset brain injury, Fetal Alcohol Syndrome) that focuses on needs/wants to generate a flexible service budget without waiting lists
- A community for all system that is flexible, with rates based on real service costs
- More accessibility or employment options for both ID/DD
- Hope that the system will ensure that people get choices to which the waiver entitles
- More sponsored residential options in Northern Virginia; currently there are non
- A single comprehensive waiver that is flexible enough to adapt to changing needs throughout the life span and which provides supports based on individual and family needs; serves military family adult with DD and accepts
- Streamlined process
- More choices of providers
- Better reimbursement rates – day support, personal care, residential; a waiver driven by services based on need; residential support for both ID/DD waiver
- High quality services that enable people with disabilities to succeed and to be active, involved community members
- My hope is that the ID/DD waiver program will be combined so that people in the DD waiver will have access to all the services people in the ID waiver have; right now it is extremely unfair.
- No wait list
- Increase rates, choice of providers, housing
- Better housing opportunities for individuals with DD waivers, many of whom need assistance/prompting to carry out normal daily functions, getting to work, etc.
- That the DD waiver will be adjusted to provide enough supports for the person to live in the community, not with parents
- To be truly universal and incorporate equal coverage for children and adults with TBIs/ABIs (traumatic/acquired brain injuries), as stated as a goal on pg. 6 of the Request for Proposals

- To have supports for my daughter that are adequate to her particular needs and allow her to remain contributing to her community (taking pride of her contributions)
- An opportunity to live on my own
- The remittances/payment for respite care needs to be higher to attract competent individuals to this important work
- To be approved for, and receive services from a waiver
- Increasing Medicaid providers available so services such as Therapeutic consultations can be utilized; increasing residential options for people on the DD waiver
- More housing in Alexandria and Northern Virginia for ID/DD
- My hopes are that my adult son will receive services that allow him to live as independently as possible as a full member of our community, not as a disabled guy who lives with his parents. He needs supported housing and supports accessing the community.
- Reduced years in the waiting list
- Simple, one-stop shopping; match services to needs; competition to reduce costs, increase quality
- To do more for the DD non-ID adult community. We are a big group that is not served.
- ID: Planning for transitioning from school age services to long-term care
- Recognition that not all ID/DD individuals are equal, especially as it relates to day programs vs. employment
- Reliable funding without indirect sneaky cuts
- Employment-related ability to earn more money while receiving waiver, especially since SSI/SSDI is counted as income
- That all individuals that are in need of a waiver, they receive it!
- To maintain consumer choice in service providers and higher pay for attendants and service providers
- Dental benefits
- No wait lists; people need services immediately, not 6+ years after they are determined to have urgent needs
- To get rid of the waiting lists so people can get services immediately upon diagnosis
- My son has an I.Q. high enough for the DD waiver, but that doesn't mean he won't need housing support
- Decisions for eligibility will be needs based as opposed to "diagnosis" based; more freedom with provider services, i.e., not limited and adjusted rate of payment based regionally
- Waivers should be related to individual needs, not mental or physical attributes
- Adequately funded waiver that meets individual needs
- Hope for adequate care and employment for young adult in community with severe ID, but great personality
- Hope that funding will be available to grant more waivers to those in need
- Hope that more jobs will be made available for additional workers
- Unlimited funding!
- Specialized services made available for specific populations through waiver services

- Thoughtful consideration of the individual's needs and wants (important for/to) the individual and a helpful process to assist providers in offering the best supports. Consider the individual's needs in the community integration piece
- Higher rated to realistically reflect required levels of service
- That personal assistance and other basic supportive services for independent living will be centralized as a state plan option
- Keep training centers open
- A system of payment that provides sufficient resources to pay people at the rate of professionals; each person can receive the supports they want and need to help them reach their dreams
- Individual will get protection for health and safety first before catering to preferences. All necessary medical, not behavioral, supports will be adequately funded now.
- Adequately funded to meet the needs of our most medically fragile and behaviorally challenged; no moves to community until improved waiver in place
- Community living is safe and truly accessible for even the most severely disabled; reimbursement rates support sustainable life, no more transferring people around
- One waiver based on the needs of the individual, as opposed to the separate ID and DD waivers
- Need respite while we wait
- Housing for high functioning autistic young adults
- Increase funding levels; MA funding insufficient for vibrant high quality person-centered community day support program; many items unfunded by Medicaid, etc.
- Independent living options for my daughter on the autism spectrum
- My hope for waiver services is to have continuity of quality staff in group homes and day programs, i.e., offer higher pay for quality staff that can grow with longevity of service
- Shorter/no wait lists
- To live with family
- That they are adequate for the number of individuals who need them; actually meet the needs of the individual
- Smooth delivery
- Guaranteed funding
- Better and more housing options for the DD waiver, at least equal to ID waiver; better pay for attendants and respite providers
- Work in area of my choice
- No gaps in services
- Increased residential options
- Easy access and navigate system; person-centered funding to match person-centered planning; flexible
- Allows individuals to chose where they live and provides supports that enable them to do so as independently as possible

- More comprehensive and coordinated approach to services. It feels very piece-meal and disjointed; more crisis intervention; more residential programs for children (under age 12)
- Combined waiver allowing easy point of entry; a safe structure based on regional costs of providing services
- DD waiver provides for personal attendant services but not for housing/independent living funding. In my family, our hope is to have provisions for both of these human needs to be met under a single waiver
- Choices for services
- Make it easier to apply and get a waiver
- More community resources! To have staff better pay! (equals better staff)
- To have quality staff; to have vendors with individual visions; have individuals hopes and dreams come true. People who think outside of the box!
- Hope that all individuals on the statewide waiting list receive services
- Hope that there is funding for individuals that are not waiver eligible
- Easier process; faster process; better reaction to feedback from State and governance (DOJ)
- Hope for services for all individuals, even those who don't meet eligibility

TOPIC: Access and Planning

Access & Planning Comments	1st	2nd	3rd	TTL
System supports the person and follow through		1	6	7
Mirror licensing across neighboring states for ease in accessing services, enable out of state docs to bill Medicaid	2	1	1	4
Psychologists and developmental specialists should not be the only professionals able to diagnosis DD to access Waiver			1	1
Need user-friendly information, plain language, on line		2	2	4
Need improved and clear understanding of case management	2			2
Needs based eligibility, not diagnosis based, include brain injury and others who fall through cracks	14	11	8	33
Improve assistance and outreach for non-native English speakers, transient people			1	1
Merge both Waivers, improve case management access	4	7	7	18
Adopt clear person-centered approaches	2	1	2	5
Integrate service systems, train human services and medical staff about resources and services	2	1		3
Consistency needed across state in services, screening teams (need to be objective), remove middle man so stat directly manages system		1	4	5
Use standard forms that follow person so nothing is missed by doctors		2	1	3

Agencies be held accountable for deadlines		1		1
One point of entry for everyone and one stop for service access and streamlined referrals	11	10	9	30
Use Va Board Biennial Assessment for Waiver implementation ideas		1		1
Develop Waiver how to packet with resources, services, key steps and activities, contact info, visual navigation tool, roadmap, etc.		1	2	3
Provide information earlier in schools and in wider community, focus on transition out of high school	1	4	3	8

TOPIC: Service Delivery

Service Delivery Comments	1st	2nd	3rd	TTL
Provider choice, independent case management	4	2	3	9
Continue consumer-directed services		4	2	6
Continue respite/attendant care options	1	2	3	6
Continue RCSC service at training centers		1		1
Recognize abilities, one size doesn't fit all	7	3	4	14
Therapeutic and residential services for DD Waiver	2		1	3
Incentivize providers to do more, serve different populations		1		1
Change transportation	3	6	3	12
Individual budgets, no set menu, no cap	3	2	2	7
Move away from SIS				
Cover video monitor support				
Offer congregate option in DD Waiver	6	3	1	10
Choice for all service providers and case management	1	2	1	4
More services embedded within providers	1	2	1	4
More quality providers	6	3	4	13
Community ICFs	1		2	3
More DD, non ID, services in community, lifeskills training, residential, budgeting	3	2	4	9
Provider follows you when in hospital or out of state			1	1
Put personal care and respite services in state plan option				
Increase housing and employment supports	1	5	5	11

Service Delivery Comments	1st	2nd	3rd	TTL
Be proactive before crisis			1	1
Increase rates o be able to pay for medical and behavioral supports	1	1	1	3
Offer respite and attendant care to people to wait list	1			
Combine in-home agency and sponsored residential, not mutually exclusive	1	1	2	4
Offer behavioral services	1	2		3
Focus on the person, not the system's needs	4	4	5	13

Topic: Costs, Rates & Funding

Costs, Rates & Funding Comments	1st	2nd	3rd	TTL
Continue consumer-directed services, expand	1	3		4
Continue environmental modifications and assistive technology funding in DD Waiver				
Fund additional service array in DD Waiver	3		1	4
Increase rates for services, currently little choice in services because rates do not attract and maintain qualified providers	29	5		34
Decrease funding of bureaucracy, speed up process		1	2	3
Increase differential for Northern VA because of cost of living is much higher	4	15	8	27
PPL, fiscal agent, is ineffective				
More flexibility in funding to allow for more creativity	3	7	5	15
Allow for siblings under 18 to be reimbursed for support		1		1
Allow for reimbursement for 24 overnight and general supervision	1	4	2	7
More portability for funding across CSBs		1		1
Consider variance across CSBs in availability of local funds			2	2
Allow parents to be paid providers	6	4	9	19
Allow coverage of funding when someone is in the hospital		2	3	5
Consider allowing rate for two 24 hour awake staff			4	4
Rates do not allow for different funding based on support needs, private sector	1		2	3
Consider alternate funding strategies to promote innovation and creativity, decrease dependency on Medicaid and government funds		2	3	5

Costs, Rates & Funding Comments	1st	2nd	3rd	TTL
DD Waiver case mgmt has never had rate increase, increase it	2	3		5
Imbed in the rates funds for transportation so providers can work directly with transportation, allows for more quality control		1	3	4
Consider all funding streams in this cost study, START, RCSCs, etc, make sure to not negatively impact other programs	2			
Need better understanding for what Waiver funds cover for CSBs, what they don't cover so services and gaps are clear	1			1
Expectations from Medicaid don't match rates	3	4	2	9
Increase funds for respite				

Location: Alexandria
Session: 6:00 – 8:00 p.m. Oct. 10, 2013

HOPES FOR FUTURE OF WAIVERS

- Capping in-home support hours so all families (or more families) can get service extending the cap (upping hours) when actually necessary
- No waiting lists, at least a minimal amount of waiver support for all families, even 720 hours a year of respite
- Congregate residential services for people with DD. Autistic people are ending up hospitalized for lengthy periods.
- A clear and comprehensive process of determining location of community homes based on more topics (ex. proximity to family, transportation, realistic job opportunities, medical offices); for the people who move in to get used to services, to be more active and integrated into the community,
Sincerely, Gail Taylor
- More providers of pre-voc, vocational services for Nov. 4; get rid of NOVA enhancements/fees for placements in various programs, FFX, Alex, R3, etc.
- Well trained and paid professionals as leads to communities, with incentives to workers, such as regular access to college level training in behavior management; redirection behavior analysis, career development
- To be able to access services
- Waiver rates should cover cost of supports developed from person-centered planning.
- It doesn't end.
- That waivers like IDEA – once eligible, determine needs
- I hope that waiver services both still exist and improve as my child grows older.

- Services need to be more individualized and more easily accessible.
- That waivers are merged and services are based on need and not what might be available in the waiver
- That the DD waiver provide community based housing
- That they don't cut my Medicaid and my SSI back
- When I grow up I want to live in an apartment with a roommate
- To provide assistance in finding employment that uses my son's full potential, knowledge, and ability
- Flexibility to meet all my daughter's needs; if only a little is left out, she can't do the rest. A road is useless when a bridge is out.
- That programs were actually funded
- That the people on the wait list can move to services sooner
- More housing options for people using DD waiver; more than 2 people with similar disability
- My hope is that waiver services are readily available to more people, easy to use, and individualized to the needs of the people receiving services.
- Higher rates paid to providers to increase options and retain quality staff
- Have work centers close to homes
- More options for services/providers
- Support/provide a small (2) group home environment
- Extra funding to pay for more than one car for multiple appointments and meetings
- That waivers provide services for clients to live and stay in their immediate community (not miles away)
- That services will be available to those on waiting list
- More employment first opportunities. If day programs are the only option, have more fulfilled activities besides collating and stuffing envelopes.
- Individual budgets based on needs, not labels
- Better pay for P.C.A.s
- That the waiver sill not "waive"* any service to an individual with profound disabilities who currently has ICF funding -
*It's called a "waiver" for a reason.

TOPIC: Access and Planning

Access & Planning Comments	1st	2nd	3rd	TTL
Expand EDCD services screeners relaying information in ID/DD Waivers				
Increase transparency of wait list for planning purposes				
Keep consumer choice		3	1	4
Single point of entry and one Waiver	7	1	2	10
Separate single point of entry from a provide agency				
Ensure military EFM offices have information on Waivers				
Incentivize direct support staff through training, college access, higher pay, etc.	2			2
Continue to support people living in home communities	1		2	3
Keep and expand training on person-centered process		2	2	4
Change the restrictive criteria for documenting eligibility for Waiver services, eligibility should be based on need vs diagnosis or IQ which may require a different screening tool, more transparent, more nuanced	5	8	5	18
Help understand how to 'answer' screening questions			1	1
Increase accurate information and outreach to diverse culturally/linguistically people			5	5
Better collaboration needed between schools, EI, etc so information is provided earlier		2	1	3
Embed information at grassroots community level		1		1
Centralize information, one stop, low cost using train the trainers model	1	1	1	3
Individualize services, not picking from a menu	7	3	4	14
Provide supports for people over 18 who fall through the cracks, "too high functioning"	2	5	2	9
Decrease levels of complexity of Waivers				

TOPIC: Service Delivery

Service Delivery Comments	1st	2nd	3rd	TTL
Keep agency-directed services	1	1	2	4
Keep consumer-directed services	2		1	3
Continue good webmaster		1	1	2
DD/ID waiver day programs at same place			1	1
Need better educated case managers, more professional, competency based case management	1	2	1	4
Assistance to find meaningful job placement	3	2	2	7

Service Delivery Comments	1st	2nd	3rd	TTL
Increase governance, oversight, accountability		1		1
More socialization activities	1		3	4
Better, quicker access to START systems		2	3	5
Better coordination with schools and service providers/CSBs		3	1	4
Need clarity of roles within education system and service providers	1		1	2
Increase day programs in the community	1		1	2
Change transportation system	1		2	3
Real clarity needed about EPSDT, Medicaid, Waivers	1			1
Clarity when moving between localities	1			1
Exceptions for military families transferring state to state	1	1	1	3
Rates to allow for low number of personal attendant hours, agencies require a specific number before they can support the individual	4	3	3	10
Household assistance, cook at home, helps with ADLs		2		2
Travel training to increase employment options		1	1	2
Same services needed across all Waivers, needs based services	8	3	2	13
Allow people under 18 to be able to provide supports	1		2	3
Equal services from all providers		1	1	2
More volunteer opportunities			2	2
More practical disability specific training for in-home providers				
More res xt (??) options for those under 18	2			2
More educational opportunities with Waiver	4	2	1	3

Topic: Costs, Rates & Funding

Costs, Rates & Funding Comments	1st	2nd	3rd	TTL
Fairly satisfied with consumer-directed hours			2	2
Keep current level of support hours				
Keep wide variety of services in DD Waiver		2		2
Process for developing Individual Service Plan is person-centered, continue it, funding is driven by the PCP process		1	2	3

Costs, Rates & Funding Comments	1st	2nd	3rd	TTL
Establish billing system based on day, month, year, not on hours			1	1
Rates should cover full cost and not rely on local funds	1			1
Take another look at sponsored residential, is it the best thing	1		1	2
Increase respite service hours	1	2	1	4
Need more people served on ID waiver	2		1	3
Increase number of people getting Individual and Family Support Fund			1	1
Services need to be flexible as needs change, go up or down	2	2	1	5
Rates need to increase across the board to attract high quality service providers	10	4	6	20
Include market basket increase due to cost of living		1		1
Increase consumer-directed to allow purchases of assistive technology, environmental modifications outside of Medicaid approved providers	1		2	3
Need to be able to get reimbursed for overnight/general supervision and vacancy		1	4	5
Increase housing options to allow people to live together (2-3 people)	4	9	2	15
Rates should be determined by staffing hours needed to support people, tied to person-centered plan	4	1	2	7

Location: Colonial Heights
Session: 3:00 – 5:00 p.m. Oct. 8, 2013

HOPES FOR FUTURE OF WAIVERS

- That it will be based on need and not diagnosis; the rates are fair; the services/frequency are not so restricted that everyone receives what they need
- Help for parents of adult children
- Individuals needing such support have a consistent source of resources, i.e., mental physical, emotional, medical
- That the waiver wait lists would be shorter to serve more people
- To merge the two waivers
- Understand the waiver services
- A waiver that my daughter can qualify for
- Clarity and availability of services and how to get them
- Crisis supports for dually diagnosed or consumers that need emergency respite
- I hope there will be enough quality providers in the community

- Waiver services that everyone who needs a waiver can be qualified to receive it
- That we work collaboratively to serve individuals in our community
- My hopes are an ongoing program to stay and help the families in need
- Includes more people (eligibility)
- Consistent
- My hope is that all individuals with a disability be able to qualify for service without a wait
- No waiting list!!!
- Help with day support for my son
- To provide the most cost effective comprehensive care to individuals with ID/DD
- Waiver services that cover independent living
- Waiver service – not only therapeutic consults but actual behavior management assistance
- Increase in residential rates for providers; mandate 2 staff at all times in all group homes
- That the system would be much more provider friendly – rates, billing, etc.
- To live the way I want to
- To become more available for more consumers – more waivers means more waiver services
- More efficient service delivery; improve speed for service authorization; stop making requests for environmental model difficult
- To see adequate housing with services for all individuals transitioning out of institutions in Virginia
- Job support
- “Emergency” waiver pool – 10% waiver slots for rapid distribution to those in hospital to prevent institutionalization

- Flexible array of services that meet individual needs and choices
- Covers nursing services for exceptional rates
- More training for PCA so that they can better serve individual with ID/DD, especially when family chose agency
- The necessary support for individuals to have a life to do activities and help
- Waiver to be less bureaucratic
- There will be no waiting list
- That my son will have support permanently; that there is no risk of losing it.
- More waiver slots; more funding; more quality providers; community education and support!
- To change the rules for case management
- That those who acquire brain injury after age 18 will be included
- Better rates for more challenging individuals
- Make sure needs of individuals and individual choice is taken into account, not just political movement; make sure reality-based
- Supported employment
- Better rates, needs based waiver; individual budgets; attendant pay when individual is in hospital
- More individuals with ID/DD be able to access needed services
- It does not throw out all the current practices; some things are good
- We love our CSB case manager; it’s my choice
- Need based for all waivers
- That persons with brain injury be included in the DOJ settlements as indicated (and not just children with TBI, but adults as well)
- That brain injury will be included in a waiver

- Waiver . . . hope to have this funded; learn from other states who have been successful in providing community supports, not segregated services
- More slots
- Single “universal” waiver
- It’s time for Virginia to fully fund, not spread the supports
- Better eligibility tool than the LOF
- Waiver services to provide quality providers, professionals trained and equipped to provide services! Rate of pay to be competitive and high enough to attract quality providers to give that service.
- To provide job coaching services
- Enhanced case management; need a higher rate of pay
- Provide funding so families have options on how to use resources to help support overall families
- That they would be much easier for families to navigate, easier to access and easier to use once a family has them
- What’s a waiver
- That every person who qualifies for the waiver got it and the state increases the funds so no one is on a waiting list
- No waiting list – automatic services
- Better rates for providers; more handicap accessible housing
- Sufficient funding for medically fragile and behavioral intense individuals
- I hope residential opportunities are available for people with all sorts of issues (behavior, cognitive)
- To have group homes for DD waiver
- Increased rates to attendants
- More understood and known about what services there are
- Have many more slots
- Every person in Virginia that needs support to live in their community receives the services they need and desire

- Some people don’t have family; these people should have the same options as others
- Dental insurance for individuals with disabilities
- I hope that people with brain injury are included in getting help and support to stay/return to communities
- A true universal/functional waiver that is inclusive of all disabilities and does not ration services based upon a diagnosis
- Secure, safe housing!
- No wait list
- That waiver will be able to fund quality services for all individuals diagnosed with ID no matter severity
- More availability for individuals with intellectual disability; shorten waiver list
- Make ICF website provide truly integrated services for all people with ID/DD, including those with most complex needs; provide individual budgets – gives individual control of money spent
- More waivers – my son on wait list for over 8 years
- Shorter waiting lists
- It is my hope that the SIS won’t be used as an instrument to deter more funding levels
- Keep family and providers of the changes in the system
- To keep NVTC opened (there are currently no homes available for my brother)
- Having workers at D19 knowledgeable and helpful instead of just saying keep him in school
- There will be additional funding for day support hours
- After high school training
- A system that is easier for families to access, with a similar process to apply for all waivers; a system that provides support for a larger amount of people

- To be able to choose places for my son to work and learn and have these places be supported by waiver (at least partially)
- That reimbursement be increased to improve the level of supports; behavior, medical, HV, etc.
- Rural area services
- Develop an understanding about what the qualifications are for the waivers and if our daughter qualifies
- Uniformity – seem to be variability around the state in how the waivers are applied
- Serves people who are not currently “eligible”
- Support for higher functioning persons
- Services for stroke patients in rural areas; none exist where I live
- That the services are divided more appropriately between the individuals on the waiting list
- Families can use waiver money to care for family members
- That all individuals that need waiver services get services
- Functionality over diagnosis; a needs-based waiver that is truly needs-based
- Shorten the wait list time
- Supported employment services align with DARS guidelines
- More waiver services available
- Individuals will be able to gain independence through the services so they are able to be successful
- Services for people that are ability based
- Less restrictive
- Better supported employment
- Allows choice, even if that choice is not the current “trend” of integrated only
- That rates will be increased so I can find attendants to do the Companion service

- More collaboration with all organizations involved in waiver implementation
- Better criteria of qualification for individuals under age 6 (re-screening babies, 2 years old, etc.)
- Adequate funding – intensive oversight of funds from closing of institutions going to community
- Insurance option for attendants
- No waiting list – anyone who is eligible automatically gets a slot
- Support more independence of the individual
- My waiver hope for Virginia is to really assist and increase waiver slots to the fresh out of high school crowd
- More providers that serve children
- Waiver providers to be better trained
- Faster process for enrolling individuals
- We need housing for DD people!!!
- Individualized budgeting
- To eliminate the waiting list
- No SIS. We hate the assessment. I’m not a number
- That they include people with brain injury regardless of age
- More people would have access to the waiver at the time it is wanted
- To be truly person-centered; to have self-directed supports
- Reimburse for work-skills training in order to get people the training and support they need for employment
- Transportation is needed in rural areas
- That the availability of waivers meets the needs
- I hope for more waiver slots in the future!
- Hope for everyone who needs waiver services to receive them; no urgent wait list
- Create an efficient, productive system
- More equitable and exponential increased access

- My son is transitioning from EDCD to ID (effective July); we still aren't on it; how long is this process!
- Fund services appropriately according to person's need
- That residential services would be provided for people with developmental disabilities
- Community knowledge
- To know what services are available
- Person-centered
- That everyone has the life he/she wants!
- Need a process for leveled/tried waiver for individuals who require intense medical behavioral support
- Is both realistic in what it can provide and allows options for those who want them
- It is my hope that the ID waiver wait list will be completely eliminated
- Less wait time to receive services
- Pre-authorization process – don't hold back on assistive technology needs – don't deny what an OT recommends
- Case management be available for the DD population
- Waivers based on individual needs – more or less, increase as needed
- To be more accessible to more people
- Serve individuals (support) for a lifetime (childhood through old age)
- Increase in the provider rate for ID community based services
- Are less confusing to families
- My sons are on EDCD waiver – dealing with PPL as a fiscal inter. is ongoing stress.
- Services become truly person-centered and the standards for providers are increased to enhance the quality of services people deserve
- Reduce state government oversight. It's our community, not yours.
- CSB given opportunity to share input since they manage ID/DD waivers.
- To fully meet the needs of every individual with a disability that will allow them to live a full and complete life in their community

TOPIC: Access and Planning

Access & Planning Comments	1st	2nd	3rd	TTL
Residential supports for both ID and DD	6		2	8
Relationship between CSB and schools				
Increase number of community-based informational meetings on Medicaid Waivers (include family networks)		3	7	10
Single point of entry	2	4	3	9
Continue needs based vs first come first serve				
Keep and increase guardian slots			2	2
Expand Medicaid in Virginia	3	6	1	10
Need portability when moving from other states	1	2	1	4
Combine ID and DD	2	6	3	11
Have one entity do the screening and publish that information statewide through all providers	3	3	3	9
Better quality oversight and assurance		3	1	4
Expand information about other resources (SSI, TOVA)		1	3	4
Emergency allocation of slots for severe accident/injuries, rather than rehab facility or nursing home placement		3		3
Funds for supporting non-urgent services	5	6	3	14
More standardized screening process		6	5	11
Need trained screeners for eligibility	1	2		3
Better instruments/forms	2	2	2	6
Have an updated, simpler, user- friendly website for DBHDS			3	3
Waivers should be based on needs/services, not diagnosis	13	5	4	22
No wait list	12	6	4	22
Expand relationships between state and schools, mandated outreach	1	1	1	3
More and better communication on getting information on Waivers, include all Support Waiver	1	2	5	8
More information (and updated) on supports that are provided	3	2	3	8
Do we have to have Waivers			1	1
more ownership, accountability, responsibility on state			1	1
Mandate outreach to military families			1	1
Need community provider system vs state system			1	1
Equalize distribution of funding and information across the state	1		5	6

Step down funding for individuals coming out of Waivers or whom need to access resources	2	1	1	4

TOPIC: Service Delivery

Service Delivery Comments	1 st	2 nd	3 rd	TTL
Keep accountability of and by service providers	2			2
Continue person-centered process	1	4		5
Keep training centers open	1	1		2
Continue consumer-directed services, differentiating agency and CD providers to maintain choice of providers	1			1
Keep everything and add to it				
Greater access to date for service planning for the future			2	2
Educate about pros and cons to legal guardianship (and its affordability)		2	1	3
Fix Medicaid transportation	2	8	8	18
Align with DRS (vocational rehab) for accessible supported employment	1	1	6	8
Families need education of rights	1	1		2
Choice and expand allowable activities	3		7	10
Increase quality trained providers for intensive medical needs	3		1	4
Decrease time for pre-authorization approval	1	1	1	3
Increase training for direct support professionals	1	11	4	16
More service providers for children	1	1	2	4
Consistent (one) training for providers prior to licensure	7	2	3	12
Choice in case management		1		1
Increase meaningful day support in community	1	1		2
Increase person-centered activities/supports that are integrated (and not necessarily Medicaid approved)	5	5	3	13
Increase accountability of consumer-directed providers	1	1	1	3
Access to affordable dental services	1			1
Fund integrated housing	3	4		7
Have individualized budgets based on service needs	25	3		28
Greater access to fiscal agents (PPL)				
Include TBI/ABI in Waiver	4	1	1	6

Service Delivery Comments	1st	2nd	3rd	TTL
Greater availability of housing		2	4	6
Increase provision of intensive services		3	3	6
Decrease number of contacts until services are available			1	1
increase hours of behavioral consultation	1	3		4
Increase number of crisis providers	3	1	4	8
Easier process to become a consumer-directed provider			2	2
Provide intensive behavioral respite options		2	2	4
More Waiver availability	2	3	3	8
Increase programs/services, particularly in rural areas	1	1		2
More support and training to person and family during and after a Waiver slot			2	2
Increase allowable services under behavioral consult				

Topic: Costs, Rates & Funding

Costs, Rates & Funding Comments	1st	2nd	3rd	TTL
Employment rates matching DRS (vocational rehab) rates	2	2	1	5
Continue Individual and Family support Fund			1	1
Don't lose number of comprehensive waiver slots if we move to a new Waiver configuration with support and comprehensive Waivers	1	1		2
EDCD Waiver needs more hours, can be used to relieve wait list, keep open for children			1	1
Continuity of availability of services that are not licensed by DBHDS – that are still Waiver services		1		1
Continue to offer slots		1		1
Continue availability of services once you get a Waiver slot				
Monthly grants that families receive from local CSBs			1	1
Rates need to reflect the true cost of services, incentivize the most integrated	3	4	6	13
Money should reflect balance between individual choice and guardians opinions		1		1
Rates need to adequately address cost associated with high needs		1	3	4
Logisticare does not provide quality transportation services		4	5	9
Cover staffing when an individual s hospitalized, can this service be offered to family	1	2		3

Costs, Rates & Funding Comments	1st	2nd	3rd	TTL
Marry rates between ID and DD system for case management	3	1		4
Need portability between states for Waiver eligibility, if you are eligible in one stat, why not in another		1		1
Reimburse for 24 hour rate coverage	2			2
Cost differential for Northern VA is unfair		1	1	2
Some funding should be available for those who do not meet eligibility for Waiver	1	1	3	5
More transparency needed in Waiver slot budgets				
Need functional Waiver to address all disabilities	7	4		11
Rates should adequately cover services for people with complex medical conditions		3	6	9
One Waiver, funding to house the DD Waiver	1	2	1	4
Funding to educate families who have school age children about the Waivers	7	7	3	17
Residential rates should account for general supervisions	5	2		7
Families need longer time to spend out family support funds		1	2	3
Regulate agencies that have competing priorities through human rights, DBHDS licensing regulations, DMAS Medicaid regulations	1	3		4
Reimburse for environmental modifications in residential settings		1	2	3
Reimburse when services start rather than a predetermined date while paperwork is being shored up		3		3
Increase sponsored residential rate	4		3	7
Increase funds for burial services	1			1
Dental, cover all services	1	5	4	10
Speech language therapy rates too low to find providers	1		1	2
Rethink how behavioral services are delivered	1	3	4	8
Increase individual budget control for person, families, guardians	16	3	3	22
Decrease paperwork, better align regulations with paperwork	3	3	1	7
Include all employment services covered by DRS in the Waiver program	2	5	4	11
Better align what is billable with what people need related to employment	2	3	1	6

Location: Colonial Heights

Session: 6:00 – 8:00 p.m. Oct. 8, 2013

HOPES FOR FUTURE OF WAIVERS

- To fully integrate all people with disabilities into their communities to enable them to fulfill their dreams!
- A coordinated effort of services that work as one to help our children succeed
- That they will adequately support a person to live in their community and with dignity for as long as they live
- Increase services, decrease in limits
- My hope is for every child to receive waiver services
- Much improved quality (attitude, knowledge, skills) of direct service providers (not owners but daily hands on folks). Money and plans will not matter if the everyday staff are not improved.
- Improved/consistent quality of supports, interactions, services
- Academic help; motivation to keep strong in their care
- Increase in reimbursement rate so that we can retain employees and offer health insurance/benefits; not so paper-driven – more time with individuals
- Professionals to be trained using assessment tools to determine the best waivers for clients
- Truly person-centered and consideration of aging in place; Americans get to retire, not adults with ID/DD
- No more waiting list
- More access to the information for parents and guardians about day to day care results and outcomes
- Better and reliable transportation services with approved companies. They are often late or no show.
- Better staffing ratios for clients with the more challenging disabilities
- There would be waivers available for everyone who needed one
- Full waiver for all
- Increase funding to providers
- That those who truly need services receive them without limits
- Better and more fair rates for providers across the board; teach more individuals; concise documentation; overnight pay for behavior issues with client
- Better transportation
- Get more services like supported living (self-directed)
- A life like yours/community
- Increase wages so we can have better quality care
- School systems need ability to offer help through services waivers
- Able to pay direct care staff a living wage – recognize their professionalism
- Information that is accessible and understandable
- I hope that all disabled could live in a home setting; more waiver slots, more funding for persons receiving or giving care; increase wages
- Include provider rates so that providers will continue to support individual receiving waiver services
- That everyone that has disabilities is able to receive what he or she needs to live a full life

- For people to live in the community, not in the institutions
- Fair rate of pay; need increase; received 2 decreases
- For people to get off the waiting list
- For the wait list time to decrease; for mental health providers to understand the waivers; mental health professionals and educators to be trained about waivers
- Suitable place for people to spend time with others outside of their home and /or work site; focused community center for special needs
- To increase in number and from a service perspective
- Services aimed at personal development and community involvement rather than just maintaining status quo
- Less confusing
- That all who are on the wait list are served
- Practical
- Hope the waiting lists will go away and all who need it won't have to wait
- Support, increase integration
- More open process for ISPs and actual permission required by guardians (families)
- Less complicated: have help to understand the waiver system and how it might help my 26 year old disabled son who lives independently with lots of support
- More slots available – waiting list too long
- Easier way to discuss issue without fueling human rights complaint
- Easier access to regulatory information
- People who work in the system know what they are doing
- No waiting list for people who need services
- Provide support so our children with disabilities are able to integrate into society
- Raise pay rate for providers
- Too much bureaucratic dictation and changes with very little change for the individual
- Help for those high functioning, but need more community supports
- Individuals and providers have services that we are proud of and improve the quality of individuals/providers and Virginia
- Separate waiver for autism/other behavioral disabilities
- More services like transportation (self-advocate)
- You can stay in your own home with all your “things” belongings
- Need a website for the My Life Redecision Process
- “Gatekeepers” who want to help and are empowered to help
- Consumer-directed services for providers other than personal care attendants; technology waiver nursing criteria applied to other waivers
- Easier and more efficient access to information that will help us make better decisions
- My hope is for a Virginia where individuals with ID will be able to truly participate in a person-centered system without the bureaucratic involvement
- Consistent application of the rules
- I hope that everyone will be able to access the services that they need when they need them. No more waiting lists. No more being denied access to the services that you need simply because your waiver doesn't support those services.
- PPL needs a lot of help and we need direct contact
- All with disabilities, especially children, eligible; more information for the public so more minorities, not middle class, know about them; higher pay rates
- More money please
- Promote independence
- Hope waiver continues for the lifetime of my son

- Too much bureaucratic dictation and changes with very little change for the individual
- Notes take too long, especially being a family member; takes time from them
- More accountability and supervision of in-home staff
- Documentation made simple
- Provide a liaison for making it through the system immediately
- Don't keep the services a secret; make sure DRS/Nurses know about HELP
- That no child or a person with a disability will not be turned down for a waiver
- Departments that work together, not just fob off work elsewhere
- More proactive support, such as job counseling
- Friendships with NTD peers and participation in activities with those individuals (without a disability, i.e., complete community integration)
- "Private duty" – RN – nursing in home for adults (or community); increase reimbursement rates for nurses (current rate ensures that staffing will always be an issue)
- Consistent accurate information across agencies
- Better pay for support staff
- Employ qualified individuals to care for the people with ID/DD; better training of staff at facilities
- Higher education and pay for home staff employees
- I want to see person-centered planning that allows for person-centered budgeting of her support needs.
- Blend the ID/DD waivers as one waiver providing integrated individually appropriate services to the client
- Empower the client; respect and recognize the rights of the clients parents and legal guardian
- Provide an opportunity for integrated work opportunities, living arrangement and educational opportunities
- Client-centered decision making – a cultural shift of the case management system
- Accountability for DBHDS to hold them to their mission statement
- Waivers be flexible enough to allow adjustment for individual needs; improve availability for as many as possible
- Simplification of the waiver system – blend it to one system; simplify the forms that are used by CSB for determination of numbers
- Hope for increased support of persons of persons with disabilities in the community via waivers, etc.
- Similar process for all waivers
- Less acronyms
- Help in finding qualified attendants reliable
- More waiver slots available sooner than 10 years
- Continue sponsor residential

TOPIC: Access and Planning

Access & Planning Comments	1st	2nd	3rd	TTL
Educate, educate, educate	4	1	3	8
Keep parent to parent support	1			1
continue funding	3			3
Continue case management services through CSBs		2		2
Standardize access across state			1	1
Waiver ineligible population		1	2	3
Single point of entry for ID and DD		8	5	13
Commitment to making sure families get information from beginning, a roadmap of services, families are a priority stakeholder		2		2
Wait list process – provide other supports while on list like case management		1		1
Make things info/easy to understand	1	3		4
Centralize information and resources				
Connect resources and organizations, collaboration and work together	2		1	3
Good training for providers, simplify things, make access easier		1		1
More advertisement of Waiver services		3		3
Balance need vs longevity on wait list	1			1
Get rid of SIS		1	2	3
Continue to plan forums like this for families				
Education for other agencies			2	2
Eligibility based on need				
No wait lists	16	5	1	22
Share information about Waivers		2	2	4
Consistent management across localities with case management and support coordination			3	3
Have pediatricians be the first point person	1	1	5	6
Guidance counselors in schools to give information on services to families				
More comprehensive screening than the one shot deal currently			3	3
Make eligibility age specific to disability, age appropriate assessment tools		1	1	2
One Waiver across the board	1		2	3

Share slots if someone doesn't take all the services	1	5		6
Trained and qualified screeners are needed				
Families need education before screening takes place, better access to information				

TOPIC: Service Delivery

Service Delivery Comments	1st	2nd	3rd	TTL
Flexibility of services should continue	3			3
Continue service	1			1
Dental care for adults	6	5	1	12
Training of behavioral specialists and direct support staff		1	3	4
Look at military and other options for service design				
Clarify path of service accessibility			1	1
Outlaw acronyms				
Increase access to respite services		1	3	4
Streamline process for consumer-directed services				
Need access to a roster of network for families				
Increase voice in case management			2	2
Need high level of training for direct support staff				
Need improvement in fiscal agent (PPL) and transportation (Logisticare)				
Examine licensing requirements for providers				
Need planning for post high/21 year old				
Provide substantial legal oversight of providers who are families		2		2
Have reasonable expectations for long term care				
More education for families	1	2	1	4
Increase integration				
Incentives for medical doctors		2	1	3
Increased understanding from schools for missed time		2	1	3
More jobs	5	2	2	9
Increase wages for staff	1	6	2	9

Service Delivery Comments	1st	2nd	3rd	TTL
Increase staff	2			2
Provide certification process for providers	1			1
Address the gap in G Tube care, family vs direct support staff	1	1		2
Continuity of nursing care across Waivers		1	1	2
Life long learning		3		3
Increase service designed by person, family (not a menu)	8	9	4	21
Use SIS for planning, not as a tool for budgeting	7	1		8
Individualized funding plan in addition to person centered plan			1	1
Increase flexibility in allowable services			7	7
Don't put a number on need (like SIS)				
Make information readily available to families, doctors, providers	3	1	5	9
Decrease workload for families in consumer directed services	1	1		2
Increase services to people with intensive medical needs	1		5	6
Increase quality of providers			2	2
Streamline documentation				
Better communication between family and providers	1		2	3

Topic: Costs, Rates & Funding

Costs, Rates & Funding Comments	1st	2nd	3rd	TTL
Consumer-directed funds towards services/activities	6	1		7
Continued sponsored residential	2			2
Continue supports	1	1		2
EDCD Waiver needs more hours, can be used to relieve wait list, keep open for children	1	1		2
Respite hours		1		1
Keep Individual and Family Support Fund		1	1	2
Keep not paying taxes for money earned under sponsored residential since the support is provided to those with difficult to care needs	6	1	2	9
If someone underspends their budget, share left over funds with others		2	2	4

Costs, Rates & Funding Comments	1st	2nd	3rd	TTL
Allow sponsored residential for families whose children are under 18		1		1
Sponsored residential needs pay for periodic relief and overnight	1			1
24 hour care for people living at home with complex needs	1	1	1	3
Rates paid for in home support increased to a livable wage	4	7		11
Increase number of people served in Waivers		1	1	2
More transportation services (they are never on time, are dirty, no AC, no show)	2		1	3
Transparent system where families have more say in policymaking	3	3	4	10
Stop being hard on families doing supported living, don't ask for more documentation. Simplify documentation	5	7	3	15
Provide pay for all days worked (families, guardians)	5	1	1	7
Add general supervision to residential rate	2	5	2	9
Embed vacancy rate in residential rate			3	3
Need increased rate based on level of need of person	7	5	6	18
Increase living options in community (home of your own, apartments)	2	5	1	8
Fund follow up for people who leave the system to prevent homelessness	1	1	6	8
Eliminate the middle man (give money to family instead of hiring nurses)		3	1	4
Unsilos consumer-directed services so funds can be used in other service categories the person needs	7	5	6	18

Location: Danville
Session: 3:00 – 5:00 p.m. Sept. 23, 2013

HOPES FOR FUTURE OF WAIVERS

- Individuals with future goals should be on the waiver until goals are met, such as Independent Living within the community.
- To provide every caretaker the proper waiver that the client they care for deserves.
- Personal assistance should stay regarding individuals who live on their own.
- More emphasis on quality of care vs. following all guidelines, dotting every "i" and crossing every "t".
- Pay the provider more money, especially if the client needs 24/7 care.

- I think it can pay more money for the work that you have to do for him, because he is like a baby.
- More person-focused need-based funding to ensure more are served with the money allotted.
- I think when you keep someone in your home, you should get paid 24 hours. You're responsible for them 24 hours. Also dental should be paid.
- Before the waiver is issued, go by to check to see if the provider is doing their job properly.
- There should be waiver slots specifically for children.
- My hopes for waiver services is that the waiting list be decreased to accommodate better. I was on the list for services, but somehow got lost in the shuffle. That was about 10 years ago, and since have had to start the process over, which was about two years ago.
- Individuals will receive more person-centered care.
- Can individuals receive both residential and person-care services within same days a week? Would like to see this happen.
- Easier to find information about the various waivers. Not feel like you may have to settle for one that doesn't meet the needs because there is a long waiting list on another.
- Flexibility to fund the person-centered plan with sound accountability.
- More open slots; better funding; more specific to the needs of the individual being served.
- Just have a waiver! No long have EDCCD – personal assistance respite, in-home, etc. This would remove most of the waiting list. Approved for waiver the second you use what you need.
- To see more people with needs to receive waiver (reduce waiting list); person-centered; to live in communities like everyone else.

- That waivers will be available for each individual that meet criteria – no waiting list.
- No wait list for person in need of services.
- A simplified system that gives people real lives with meanings as they define it.
- Increase in staff to provide more one-on-one when needed.
- Reduce excessive wait time for waiver slot and let the person decide how funds are allocated.
- Provide community-based quality care with person/individuals needs et on a case by case basis.
- More inclusive, more comprehensive, more individualized, more client input.
- Increase in available waiver services, easier access, more availability in the community, easier proves for individuals and families.
- We need a support group in Danville.
- The level of care (day services) needs to increase for those with increasingly intense needs.
- Truly person-centered services; eliminate waiting list; waiver that meets individuals needs.
- I hope that waiver services will encourage companies to build more places to house clients instead of have a long extend waiting list. Everyone deserves a place in the community. Thank you.
- Supports that focus on individualized support in the community. True integration.
- I would like to see more choices and control given to those on the waivers. Allowing those on waivers to choose how to use the funds available.
- Less waiting time for services.
- More people having a waiver slot; making the process shorter, not such a long wait list.
- Focus on streamlining the reimbursement process; day support, residential support, specialized supervision.

- Ensure that the smaller providers are not “choked off” by larger entities.
- Individuals have ways of making their voices heard even when they cannot speak or verbally communicate.
- Our daughter is still on the waiting list for the ID waiver. I would like to see more waiver slots and some specifically slotted for children.
- Waiver funding for only a service specific (example – residential day services therapy waiver)
- My children like working in a sheltered workshop where they communicate with individuals like themselves. The workshop is like a normal business place. I hope that waiver services give them the money they can use for their meds.
- Quicker access to waiver services; more services available under waiver; better education to parents about waiver.
- Provider/service increase; decrease paperwork.
- Flexible changes based on needs/wants.
- Number of individuals with intense needs – needs to be addressed; DOJ settlement with work first is not always feasible for those with intense needs.
- Ratio of individuals to staff in day programs needs to increase with high-intensity levels – rate has to go up for funding to be appropriate to ensure staff are compensated for hard work and able to truly meet individuals’ needs.
- My hope is that a waiver is more readily available to individuals and families that need them.
- I want the waiver to be available to our special needs daughter while she is young, when she will benefit from it the most.
- That the individuals on the waiver waiting list received services within a specific time frame, rather than being on the list for years and years. Meaning service available within the community and to have more providers services such as SPACH for adults.
- Shorten waiting times; individual is truly at center of services; take long range view of services.
- Reimbursement rates are adequate for providers to be able to staff with more than 1 staff per 4 bed homes.
- Change the residential rate based on the needs of the individuals. Tier 3: \$18.00, Tier 1: \$12.65, Tier 2: \$15.00.
- One comprehensive waiver for ID and DD. More providers in all areas of Virginia. Greater community supports, higher reimbursement rates for services, more supported employment.
- Combine ID/DD waiver.
- I would like to see a base fee to cover the hours that an individual receives support and is not engaged in training “skill building” activities. Set monthly fee.
- Just trying to remain on top of all changes.
- It all comes down to funding. How does Virginia increase ID waiver slots substantially? The Danville area usually only gets less than 20 slots per year. There is already a waiting list of 100-200 +.
- Integrated system of care including DD population.
- Consolidate the ID/DD waiver with emphasis on inclusion, integration.
- Receive waiver quicker to get a job and have to _____. We live with my grandma. Waiting should not take 13 years.

TOPIC: Access and Planning

Access & Planning Comments	1st	2nd	3rd	TTL
Continue availability of waiver	3	2	1	6
Continue discussions with housing in this region				
Continue to allow for independence & resources once you receive waiver services				
Continue person-centered thinking training				
Continue to focus on the person by most providers				
Make transition work more widespread, more help with school-age to adult hood) more help with employment	5	3	5	13
More help with transportation	3	3	2	8
More waiver slots	14	5		19
Earlier Access to slots	5	11	4	20
Qualified trained providers	1	3		4
Advocacy for parents to navigate		2	6	8
Trainers to train independence while living in the community			3	3
Streamline the process & individualize services as opposed to what is best for the group	1	3	1	5
Mandate # staff per person (like in public school)-need for quality staff	1			1
Standardize information across state	2	3	5	10
Flexibility of services for all levels of disability	4	3	6	1
Conduct public awareness to that people know where to go to get services-like autism awareness	2	6	3	11

TOPIC: Service Delivery

Service Delivery Comments	1st	2nd	3rd	TTL
Continue EDCD Services	2	1	1	4
Continue Person Assistance for in-home		3		3
24/7 residential supervision	4	2	1	7
Combine waivers			2	2
Work on how supported employment income impact social security benefits	5	3	4	12
Increase respite			3	3
Remove CARF fee for accreditation				
More support for in-home individuals to live more independently	10	4	2	16

Service Delivery Comments	1st	2nd	3rd	TTL
More services in community in Southside Virginia for individuals coming from the training center		3	3	6
24/7 residential funding	4	1	6	11
More community involvement	3	1		4
Flat rate in group home	6	10	2	18
Retirement from day services	6	9	6	21
Case management choice	3	7	3	13
Better transportation		2	5	7
More person-centered based on individual need	2			2

Topic: Costs, Rates & Funding

Costs, Rates & Funding Comments	1st	2nd	3rd	TTL
Continue the rate for case management				
Hourly rate increase for personal care (increase please)	7	2	5	14
Continue to provide work resources for individuals to continue to work			1	1
Keep retroactive payment for attendants				
Periodically check on the care providers to ensure that they are providing quality care	2	3	4	9
Ensure funding incentives for independence and integration		4	1	5
Waiver funds need to be given parents who can use the funds as need for their child-more flexibility in waiver budgets	2	1	3	6
Increase the number of waiver slots in Danville area	1	2	3	6
Increase rates to pay a livable wage to staff and to recruit quality staff	1	2	3	6
Increase funding for staffing for people with complex behaviors and complex medical conditions	6	3		9
Increase day support to provide for true integrated services			2	2
Allow for individuals to have greater personal funds to help meet their needs and not impact their eligibility for waivers	3	2	5	10
Increase DD Case Management rate		2		2
Change how funding is calculated (based on minutes/hours) not conducive to life	7	9	5	23
Need to allow for funding(support) when a person is in the hospital	6	1	1	8

Costs, Rates & Funding Comments	1st	2nd	3rd	TTL
High intensity rate not enough to cover staffing costs, needs to be increased	5	1	3	9
MFP need to accommodate people who need more than 4 bed home..people will not take people with greater needs because they need more staff support	1	2		3
Issue waivers according to the urgency of the need and not the client		2	2	4

Location: Danville
Session: 6:00 – 8:00 p.m. Sept. 23, 2013

HOPES FOR FUTURE OF WAIVERS

- Rates flexible and meet his health needs people.
- Quicker process for benefits; more specifically tailored to individuals needs since there is a broad spectrum of ID/DD.
- I hope to get a slot now soon. There are not enough slots to go around.
- Less paperwork.
- Provide for needs of each person/family.
- Make ICF not needed.
- For flexible waiver supporting all levels of ID/DD in person centered manner in inclusive settings.
- To offer a variety of services to accommodate all of the individual's needs.
- Provide a seamless array of services to support individuals in following their dreams in the community, ranging from appropriate crisis services to respite to supported employment.
- More services for people who are higher functioning.
- Hopes for waiver services in the future; more frequent communication from state officials via home visits, phone calls, or e-mails; more evaluation of home and needed support.
- Coordinate ID and DD.
- Provide adequate services based on the need of the individual.

TOPIC: Access and Planning

Access & Planning Comments	1st	2nd	3rd	TTL
Single point of entry is helpful to families			1	1
Scoring for waitlist was helpful (consistent, fair structure)				
Independent Support Coordinators provide choice and no conflict of interest on DD Waiver			1	1
Provide a clear step-by-step process for people/families to learn about services/supports	4	2		6
Increase number of people who can find people eligible for services	1			1
Address conflict of interest with CSBs providing case mgmt services	2	1		3
Increase services for people with less support needs, milder disabilities should get something, people falling through the cracks	1	5		6
Find a better level of functioning tool to find people eligible (people falling through cracks)	1	1	3	5
Increase information on available services for people who are aging				
Level of Functioning tool 1not consistently applied	1		1	2
Expand services to support ALL needs	1	1	3	5
Change culture of case mgmt to be more supportive of inclusion in communities				

TOPIC: Service Delivery

Service Delivery Comments	1st	2nd	3rd	TTL
Better transportation services				
Quality improvement system should not solely rely on utilization review	1			1
Quality should be linked to outcomes and families	4	2	1	7
Combine waivers			2	2
Work on how supported employment income impact social security benefits	2	1	4	7
Decrease the amount of paperwork that drives the system		1	1	2
Maintain the flexibility of the Individual and Family Support Fund	1		4	5
Maintain flexibility in choice of service coordination (DD Waiver)		3		3
Waiver needs full array of services to support all types of needs	4		1	5
Services need to support inclusion				

Service Delivery Comments	1st	2nd	3rd	TTL
Service definitions needs to be more flexible to support real life (not service focused, but life focused)	1			1
Caregivers need more support and assistance with financial matters	2	2		4
Need flexible budgets to support individual/family needs		1		1
More equity between ID and DD Waivers		2		2
Lack of provider choice in case mgmt (ID Waiver)	1		1	2
Increase behavioral supports (people are falling through the cracks)		2		2
Increase agency respite providers (so poorly funded that no agencies providing respite)		1	4	5
More fluidity (if savings from one service, use it to buy another service)				

Topic: Costs, Rates & Funding

Costs, Rates & Funding Comments	1st	2nd	3rd	TTL
Keep consumer-directed supports	1	3		4
Moving in right direction with focus on community services – need to fund more				
Keep sponsored residential	1		1	2
Need more transparency in how savings from institutional settings are being reinvested in community settings		3	1	4
Make sure funds are available for people who are transitioning to community setting				
Increase reimbursement so that support workers have a livable wage	1	2	1	4
Pay parents to provide supports to their child	2			2
Rates do not adequately cover costs for support to people with high needs resulting in out of state ICF placements	1			1
Increase funding for community supports				
Increase incentives for providers in rural areas, there is little choice	1			1
Decrease fiscal incentive to provide more services/supports than are necessary				
Lack of consistency in eligibility standards, case mgmt leaves people/families at mercy of interpretation	3	1		4
Increase Day Support rates so there are incentives for integrated employment		1		1
Use individual budgeting, individual control	1		4	5

Location: Hampton
Session: 3:00 – 5:00 p.m. Oct. 3, 2013

HOPES FOR FUTURE OF WAIVERS

- Phase 1 tasks, phase 2 tasks get done
- Stop the use of the reward and pay people with intellectual disability
- More options for in-home support services; the application process should be simplified; area DSS employees and CSB employees will actually be familiar with waivers and process; shortened waiting list or increased options to receive services
- Realistic regulations that balances paperwork requirements with service provision
- Application process user friendly
- My hopes are that waiver services becomes more of a reality quicker for those that need it.
- Waiver services be easier to access for those in need and to include dental services that appeal to providers
- More individuals services – community outing
- Funded well enough to allow providers to pay staff well enough to hire professionals, not just bodies
- Waiver will not stigmatize people who use them
- To be able to provide services to majority of people with ID, thus lessening the number on the waiting list, and be able to sustain the program
- Allocate monies to eliminate any waiting list
- Day support waiver becomes a service paid for by Medicaid just as psychosocial rehabilitation services are for the SMI population
- They will be available to those who need them and not be threatened by budget cuts; information be readily available to families who need these services.
- Increase in rates for Virginia
- No waiting list! Give people what they need to have a life in the community
- Have better and appropriate service for people with disabilities
- Funded well enough to incorporate most current technologies into service delivery
- Hope for easier access to services and for them to make them aware of the services available
- Everyone needing urgent services is able to obtain a waiver slot when needed.
- No wait list
- Everyone can have a service that fits them.
- No waiting list
- My hope is that everyone who needs a service can have access and funding for that service at the time of need.
- Efficient process to get folks off waiting lists and receiving services
- That larger facilities will not be discriminated against, but rather given to a resident in need
- That everyone get there full service
- Continue the same quality of care
- Tiered rate system to cover costs for those with more challenging needs

- One waiver that provides a menu of services to support individual's needs throughout life.
- More organization; shorter wait list and wait times; better rates; more funding
- Reimbursement rates that fully cover the costs of services
- Rates that support quality services in a range of settings
- To be able to serve all individuals in the state in need of service
- To make the process easier
- Unlimited amount of resource and money for our individuals to "have a life like yours"; no limits
- More readily accessible resources available
- Voucher system
- That the process becomes quicker; that there is no waiting list
- Waiting lists are kept to a minimum (Too many people who need services can't get them.)
- Like any health issue, that there are no waivers; people with and without waiver access services they need as they need them.
- Services available for all individuals in Virginia
- Increased rates
- All individuals with disabilities, regardless of income can receive services.
- Hope Baby Boomers and Seniors with ID have a voice
- Individuals have more choice and control over supports they want and receive (services are provided without service limits).
- Waiting for approval to get one; I'm not familiar with the services to express my hopes for the future.
- Hopes for our individuals to have more housing and more individual services
- Everyone gets services regardless of having a waiver or not
- Uncomplicated
- I hope the services will truly become more person-centered, that the community (neighbors, cities, counties) become more receptive to individuals living in the community and the rate becomes fairer for services provided by providers.
- The waiting list is eliminated
- ID/DD will include respite hours (At this point I believe only EDCD waiver includes respite.)
- No one has to wait for services
- More slots available
- Waiver that includes acquired brain injury
- No waiting list for individuals with disabilities
- No wait list; not have services contingent upon waiver
- Universal waiver
- Respite services would be covered
- More options for residential services
- Waiver services need to be specific to the needs of the consumer!
- One-on-one day options to those individuals that need and want it
- No wait lists
- Available to those with IDD
- To be available to more people
- More waivers to be available to individuals that need them and that they also can access them sooner; consider rate reimbursement and ensure that rates are comparable to service rendered

TOPIC: Access and Planning

Access & Planning Comments	1st	2nd	3rd	TTL
Have opportunities like these public forums to keep getting feedback	3	1	2	6
Continue person-centered planning and PC Thinking training		3	2	5
Schools need better access to information	3	1	2	6
Military needs info on services				
Need better access to state websites		1		1
Parents in the school to adult transition timeframe need more education on adult services	1	1		2
There needs to be more help for appealing denials				
Need a 'one stop' shop as the source of information (too complicated, time consuming and frustrating now)	1	7	5	13
Privatize case management		1	3	4
Continue case management, a good link to resources		1	2	3
Need consistent case management practices (different in DD and ID Waivers)			1	1
Need parent education	1	1	2	4
Information on Waivers and services needs to be more widely available (how to find case mgr, what are the different waivers, who should I go to, what is criteria for EDCD waiver)	17	4	1	22
People need to get what they need from a prescription if we treat long term care as any other health issue (we don't need waivers)	5	3	5	13
No wait lists	10	7	4	21
Need more funding for system	4	7	6	17
Don't label people, stigmatizing				
Increase focus on a person's gifts and strengths	1		1	2
Recognize today's youth with disabilities and families are very different than those 20+ years ago		4		4
Support families so they are not afraid to ask for help			4	4
Increase number of times team comes together to plan for overall long term needs			2	2
Help people with disabilities develop non-paid relationships in community		2	1	3
Make more friendly the paperwork, forms, and process			2	2
Decouple SSI disability from medical/health care provision	2	4	5	11

TOPIC: Service Delivery

Service Delivery Comments	1st	2nd	3rd	TTL
Continue Consumer-Directed Services				
Continue existing services on ID Waiver	1	3	4	8
Keep person-centered process and training		1	2	3
Continue START crisis services	1	1	4	6
Continue work and job opportunities		1		1
Continue skilled nursing services	4	3		7
Maintain strong network of providers				
Continue respite services for families		2		2
Continue trend of group homes	1		1	2
Continue monthly case management visits and enhance case management services				
Have 6 bed group homes	1	1		2
People have their own rooms				
Continue Community Resource Consultants				
Have provider round tables				
Provide center and non-center based services	1			1
Combine Waivers into 1 Waiver	3	2	1	6
Have a menu of services that changes as needs change			2	2
Add MH services back to ID Waiver	1		1	2
No wait for services	5	5	2	12
Services/supports should be geared towards age and ability	1	5	1	7
Have a different Waiver for medical needs	1			1
Need more providers of crisis services			2	2
Have transition services for youth	1		1	2
Increase staff providing services and case management	2	1	1	4
Privatize case management	1			1
Increase behavioral services in the home			1	1
Have no more than 5 in a group home		1		1
More oversight needed for families providing services			1	1

Service Delivery Comments	1st	2nd	3rd	TTL
Change '30 rule' for case management to once a month				
Have more allowable activities per service	2	2	2	6
Expand transportations services, improve quality and reliability, access		1		1
Ensure accessibility to community buildings				
Dental care for adults	1		1	2
Need crisis hospitalization for people with ID	3	2		5
Provide education for providers of crisis services, including law enforcement		2		2
Need better coordination of services	2		1	3
Certification of DSP				
Access to planned respite			1	1
Expand job/work opportunities		1	2	3
Provide education of START services		1		1
Expand residential models/options		2		2
START services for youth under 18 yrs old			2	2
Increase medical assistance for people living at home				
Redefine criteria inside Waiver for services				
Change regulations for environmental modification (so not just available for own home)				
Increase education of all supports and services				
Change process for authorization of services				
Put more emphasis on service provision than on documentation			2	2

Topic: Costs, Rates & Funding

Costs, Rates & Funding Comments	1st	2nd	3rd	TTL
BHDS should continue to manage the Waiver			1	1
Continue respite allotment		4	2	6
Continue current system so we 'do no harm' to those receiving services (fear of service reduction)	2	2		4
Change that Money Follows the Person get slots immediately upon leaving training center, but people in community still wait for years			2	2

Costs, Rates & Funding Comments	1st	2nd	3rd	TTL
Need vacancy rate in case of emergency so person will have staff at hospital and a place to come back to			7	7
Need higher wages for staff	9	3	4	16
Incentivize smaller homes				
Change that providers are having to take a loss now				
Stop CARF accreditation (makes it hard to do supported employment)				
Rates too low to find and afford quality providers		1		1
Rates need to increase to be more in line with MH system	22	1	1	24
Combine ID & DD Waivers	1	4	6	11
Don't combine ID & DD Waivers				
Increase rates for respite and all services	1		1	2
Companion services are overlooked		3	2	5
Concerns about authorization protocol				
Change that case managers not reimbursed for training center discharge time				
Need smoother transition from training centers to community	1	2	1	4
Prioritize funding so it supports state initiatives/priorities	6	1	5	12
Got to a voucher system funding services by need		3	2	5
The model should fit the person, not try to fit the person into the model		8	2	10
There is no in between – either given emergency slot or on wait list			2	2

Location: Hampton
Session: 6:00 – 8:00 p.m. Oct. 3, 2013

HOPES FOR FUTURE OF WAIVERS

- Waivers should be portable, should not lose waiver when moving state to state
- Communication between military and other support communities
- HIPP for military insurance
- START program for all ages
- Future hope – more equitable allotment of waivers around state
- Clarification of what each waiver actually does; availability to all that need service; no wait lists
- More respite for caregivers
- That require additional/special supervision (sheltered work centers) – special needs brother
- It follows person so we have more innovative personal solutions
- High quality day programs for those that cannot work
- Supported employment for all regardless of family income, beginning in middle or high school – living wages
- Wheelchairs (durable medical equipment) that meets persons need, not Tricare; idea of what works
- Better pay and benefits
- Not forced to retire because you are a little broken
- Organized hiring procedures; also no need to reapply if working for others
- I hope all people who need services will receive services
- That every person in Virginia can live happy, free, productive lives by getting the supports they need
- Administer them fairly; make the application process similar; continued reevaluation for life; funding remains abundant; change society's opinion
- That people get the services they want, how they want them, by people of their choosing, to have a life like mine
- My hope for the waiver in the future is for people to simply be served and not sit on a wait list for years.
- I hope that more individuals needing services will be able to be accommodated in the system.
- Better well-trained providers who get benefits and good pay; better, more educated assessment teams for getting waivers; more consistency in delivery of services
- Living in a group home for my son, supported employment, transportation, recreational opportunities
- Residential services, job coaching, employment, speech, PT, OT services
- Adequate housing and support to have a life like yours
- Tricare cover durable medical equipment, like glasses
- Allow PCAs to be in the home for all ages with justification
- I would like to see a waiver available for individuals that are not able to obtain employment in the community
- Military or others to move in and out of states; transfer to other states
- Eliminate long waiting lists for waivers and services
- “Out of the box” community living options beyond group homes; help with apartments, home ownership, microboards, etc.

- Aides in colleges that want to do it
- Job support; pay services; supervised care
- More than 1 training center; needs to stay open for those with complex needs.
- Services should not take years to become available to those in need
- Ability to have higher income and still be eligible for waivers
- More waivers, less waiting
- Better pay and give benefits for PCAs
- Christy to have support for the rest of her life
- My hope for waiver is that waiting lists decreased, and it will go from crisis management to meeting needs of people with a job as they need it. Maybe stagger waiver so services can be gotten as needed rather than all or nothing
- Dental coverage after age 18
- Residential rates to increase to provide the necessary medical attention for individual come out of the institutions, along with day support rates and the necessary training (g-tube, feeding, aspiration, etc.)

TOPIC: Access and Planning

Access & Planning Comments	1st	2nd	3rd	TTL
Continue to provide information to community partners, children's hospitals, other parent organizations				
Continue to allow ARC as a provider (intake process)	2			2
Continue to give out Waiver information at school IEP meetings		1		1
Need one door to access information, systems navigator	12	3	3	18
Eliminate wait lists	5	4	1	10
Need transparency (brushed off when seeking information)		3		3
Military families need access to information and portability of Waivers (misinformation from professionals)	2		5	7
Need different entities in community to create a safety net between agencies so no one falls through cracks		1		1
CSBs are understaffed, miscommunicate	1	1	1	3
Wait list deters/intimidates people				
Privatize case management	1		4	5
Simplify (too complicated, complex, need best practice, need CSB checks and balances)		8	7	15
Need education on Waiver services		3		3
Make eligibility process less intimidating	2			2
Make access to minimal services possible	1		2	3
Help aging families	1	1	1	3
Increase access to case management	1			1
Need tool for eligibility/assessment that captures accurately				
Need standardization between agencies				
Need central database of providers				

TOPIC: Service Delivery

Service Delivery Comments	1st	2nd	3rd	TTL
Training centers should remain the same				
Keep group homes	2	1		3
Keep sponsored residential			1	1
Continue consumer-directed services				

Service Delivery Comments	1st	2nd	3rd	TTL
Continue services facilitation				
Continue respite service	3			3
Keep mileage reimbursement for medical appointments				
Keep Health Insurance Premium Payment Program (HIPP)				
Maintain services for people with intensive medical needs	4	1		5
Reinstate respite hours	1			1
Revamp in-home services to meet need (more hours) so person can stay in home	4			4
Provide more incentives to employers to hire people with disabilities	1	3	1	5
Extend authorization length of time				
Revamp crisis management services across people, all ages			1	1
Allow family members to be paid as aides across all ages				
Establish a central communication/data portal				
More retirement services				
Need consistent, high quality day support services	1	1	2	4
Rules for services facilitators on how to transfer facilitators (individual needs choice without having to get approval from existing services facilitator)				
Improve consumer directed services				
Lower case loads for case managers, need more case managers				
Need consistency in case management across all waivers	1	2		3
Completely overhaul transportation system (broken)				
Dental care for adults	1			1
More preventative medical care for all ages				
Need formal training for services facilitators				
Close sheltered workshops			1	1
Need information about what Waivers are all about	1			1
Need more residential options (apartments, homes of their own, independent living) and out of the box ideas	4	4	4	12
People can get married and receive supports they need		2	2	4
Need postsecondary options (college)	1	2	3	6
Better transition services from high school		2	2	4

Service Delivery Comments	1st	2nd	3rd	TTL
Better transition services from training centers				
Supported employment for everyone regardless of income		3	3	6
Better quality of personal assistants	1			1
More choices for how services are defined		1	1	2

Topic: Costs, Rates & Funding

Costs, Rates & Funding Comments	1st	2nd	3rd	TTL
Increase funding for transportation		4	5	9
Rate should match cost of living increase		4	2	6
Intensity rate = behavior intensity		1	3	4
Increase reimbursement rates			2	2
Flexibility to pay staff with higher education/experience	4	5	4	13
Staff grow into their job	1		1	2
Change IDOLS/DELTA authorization systems				
Fix that residential programs not taking individuals from training centers due to current rates, rates don't assist in the intensive care that is needed		1		1
Bill for safety supports during day				
Better pay and benefits for personal attendants	2	5	4	11
Provide financial incentives to employers to hire people with disabilities	16	1	1	18
Pay DSPs better (with provider reimbursement)		3	2	5

Location: Lynchburg
Session: 3:00 – 5:00 p.m. Sept. 25, 2013

HOPES FOR FUTURE OF WAIVERS

- Let the providers do the job they do best, provide services without the excess paperwork where 1/3 of our . . .
- All people who need services get what they need to live independently in the community. No waiting list for services, a system that is not so difficult to access in order to justify need of individuals.
- My hope is that the waiver system will continue at the same rate or improved rate (payment) for services. I pray those that now have waivers will not lose them. I hope for fairness.
- More funding to be allocated regularly so more people have access to needed services and not wait years! For DD & ID waiver paperwork to be more aligned with each other and not two sets of completely different paperwork.
- The waiting list is decreased so that individuals who truly need services will be provided that opportunity.
- Ability for our folks to have jobs and not lose waiver funding.
- Resources go to paper instead of direct services.
- That the DD waiver would provide the option for living in a group home. That the rate paid to workers (caregivers) would increase so as to attract more quality people to work with individuals on the waivers.
- Funding for special transportation – wheelchair accessible vans.
- Sufficient number of slots for everyone in need.
- To offer more education to the parents of young children on what service options are available for their child. More slots!
- Waiver services will provide a process for enhanced funding based upon the individual's needs.
- Who is pushing to close all the training centers?
- Privatize ID waiver case management equals consumer satisfaction.
- Cost for services are equitable and reasonable so that waiting list can be reduced and eventually eliminated; people with mild ID/DD can access supports and services; CSB has a better way or format to prioritize and those most in need on the urgent waiting list;
- Living wage and benefits for those providing consumer-directed services – also more over-site of providers.
- That it is set up and have funding for the future. There are so many individuals placed in the community and living in the community that depend on these services. Raises for providers; less paperwork so that direct staff can do more with the individuals we care for in group homes and day support, etc.
- Parents are contacted, offered information about waiver when child is young. Too many parents feel stressed when their child is aging out of school and they can't afford the next step.
- Better access to better medical care; reconsideration of sponsored residence model group home (4 or less).

- All in need receive what they need when they need.
- More slots earlier so consumer can get earlier intervention they need; better crisis support across the state; better knowledge of waivers so parents sign up as soon as possible rather than later.
- People get the amount of service they need; rates are such that quality providers are everywhere; services are flexible and accessible; people are all part of the community; people are afforded protection and advocacy.
- To not only be more consumer friendly, but provider friendly; realistic expectations for the provider in documentation and regulation.
- More available waivers; no more SIS assessments completed by case managers.
- More money for waivers; realistic expectations for the money provided.
- More funding, more waivers filled
- Logisticare is not reliable or effective. Late, does not show up, vehicles are unsafe.
- More available slots for people to receive services they need; increase in waiver rates; Less stringent requirements and documentation.
- More money, less bureaucracy, needs based, more flexible, covers housing.
- That every person who has an identified need for ID waiver can receive services without delay because of lack of funding; that Medicaid would be more practical in the expectation of services rendered and documentation.
- Development of meaningful community resources for individuals with ID/DD.
- Lower case loads for case managers; waivers for all ID individuals; no more SIS being completed by case managers.
- That there would be behavior support availability if needed; have had a hard time finding behavior support.
- End the wait list; cover transportation, housing, day programs.
- Rates sufficient to serve all individuals in all areas of the state.
- Increase supported employment reimbursement to mirror DARS services; provide more residential services to the DD waivers; make ID/DD waivers more similar to services provided.
- Equitable distribution of waiver funds; waiver slots to meet the demand.
- More streamlined between ID/DD waiver services – more similarities regarding the way services are accessed/begin/monitored; increase funding opportunities to allow more individuals with needs to be active on ID/DD waivers – reduce the wait list time; possible increase in rates for DD waiver case management/more comparable to ID waiver case management.
- That many more become available for so many people on waiting lists; that those who receive money can make decisions about how money is used (with help).
- World peace.
- To provide adequate funding to insure high enough wages for providers to assist my son to live as independently and productively, while living a happy active community life, as possible.
- Have more slots.
- Expand services.
- More community involvement; easier access to medical equipment and better equipment; better medical care access without red tape if person has no legal guardian/family (easier process).
- Problems with regional advocates - what is their role other than to talk about ARs? Do not investigate anything.

- Person-centered planning; flexible supports to align with varying needs of the recipient; acknowledge the importance of service providers by offering fair compensation and benefits; no waiting list.
- Improve residential rates for congregate group homes to allow for person-centered services; create gap filling crisis services to assist START.
- Higher wages for caregivers.
- Increase bed capacity of sponsored residential homes; increase rate amount for sponsored residential services.
- Handicap accessibility in public setting still issue.
- Shorter wait time for approval; getting information to parents when children are small; clarity about what is available, how, when, and what it will look like.
- Day support will continue to be offered; reimbursement rate for day support services will increase to support 1-3 staff to service recipient ratio; growth and development in maturity and skills will be a primary measure of quality of services and potentially be reflected in reimbursement of providers.
- START cannot take TDDs and we need a true crisis response – safe place for folks with ID who are in crisis. This is not START; address hard to serve people adequately with waivers.
- ISAR/IDOLS system is more user friendly for agencies; approvals done in a timely manner so funding is not held up for agencies providing services.
- Need more available waiver slots.
- To continue the services that are offered! Continue to allow private contractors, like LACIL.
- Will recognize that increased rates for residential services are vital to provide quality support.
- Quicker approval for service authorizations.
- CSB running homes and case management is a conflict of interest.
- Increase waiver slots; make it easier for providers to get hours needed to help individuals; make the process make sense; have ISARS 30 days early does not make sense.
- Shorter wait list.
- People approving ISARS look more at the person centeredness of a plan than just focusing on the hours mostly.
- Waiver services will increase to accommodate more services in depth for individuals.
- That it continues to serve in the future to all community to those who needs H.
- Funding for waivers for those with brain injury, who may not have a diagnosis that fits “ID or DD”.
- Tiered system based on level of need – flexibility to move from tiers as skills/needs increase/decrease; flexibility similar to DAP funding so that plans can be individualized (person-centered) to best meet individual needs.
- PPL – better services required, and many employees are unprofessional and apparently unqualified; lack of good customer service skills.
- Streamline the hiring and pay-out process with PPL for consumer-directed services.
- Educate family early on their available resources and options; advocate for individual.
- To provide services for more individuals in a timely manner;
- To eliminate wait list; group homes; respite opportunity; nutrition services for healthy lifestyle and interaction with medications on dx.
- Employment/work opportunities
- Rich, full lifestyle.
- Services approved in a timely manner; rate increases for agency and consumer directed all services; less

documentation and more focus on services; too much oversight, i.e., licensure, human rights, auditors.

- Have services flexible enough to accommodate “individuals” who have various needs; No road blocks to adding services as needs arise; provide attractive “pay’ for those persons providing services to attract quality individuals.
- Higher pay for those working under waiver services.
- Funding services for all supports all inclusive instead of bottleneck.
- For services to be accessible; to know that wait; to be based on function; reliable.
- More efficient; be able to contact someone who has answers and not get answering machine.
- Salaries are affordable for people to work in this field and provide for themselves and family decently; some type of major medical insure is a must for employees that is affordable; individuals are provided one to one services and not be grouped beyond their needs and not receive adequate services.
- More person-centered – “really focus on what the individual desires”.
- Blanket funding each year to meet the urgent lists; accountability for CSBs to share all waiver services with all families; faster approval of services proves – ID slots.
- No waiting list, more services, more resources, pays private providers for social work services; less focus on documentation and more on client; pay parents of minors to be care providers for their child.
- That funding will really be tailored to individual needs/supports (especially after an individual’s needs are documented by the SIS).
- Better ways to easily access the website for better usage.

- Elimination of the waiting lists; supports that provide for more than a minimal life; rates that provide stable supports to individuals and fair wages/benefits to support personnel.
- My hope for the waiver services is that my two children get their waiver so I can get some help. They have been on the ID urgent list for 8 years, reviewed the last 2 years, and told they are too stable.
- Why does everyone need an AR. Process, reasons, test, etc. are very unclear; negates individual choice.
- Consistent interpretation of both Human Rights and Office of Licensing Regulations from specialists in areas that are not clearly delineated in regulations.

TOPIC: Access and Planning

Access & Planning Comments	1st	2nd	3rd	TTL
Continue working closely with early intervention	1			1
Person centered planning groups effective in planning with individuals	1		2	3
Level of functioning gives a concrete way (??)				
Have a system for determining (??)				
Continue urgent designation of the waitlist				
Keep access to EDCD while on waitlist	1		2	3
Tier scoring system is helpful			3	3
Waitlist committee made up of a variety of stakeholders, not just CSB		2	1	3
ID case management through CSBs are great to work with and responsive				
Their person-centered (??)	1	3		4
Referrals not coming in after child turns 18, no psychological	1	1	1	3
Increase development of community awareness	1	3		4
One access point for all waivers	16	8	5	29
Better coordination across services and stakeholders	4	4	3	11
More training on waivers and how to access		1	2	3
Do away of IQ designation – functional level vs diagnosis	1	1		2
Move locations for screening for DD Waivers– come to the individual to do the screening			1	1
Need more case management (ID and DD)	1	4	2	7
Increase funding for slots	11	9	2	22
Change way waitlist handled by CSB				
Look at other states who have no wait list and model after them	5	7	4	16
Lack of communication of who is on waitlist			1	1
Case managers/service coordinators do not have complete and updated list of providers		1	2	3
Case loads are too large for case managers and service coordinators to manage	1	2	2	5
Need centralized training for case management in DD waiver				
Need transparency with KeyPro		2		2
Justifications too strict	6	6	5	17
Replace cut in respite hours		3	8	11

TOPIC: Service Delivery

Service Delivery Comments	1st	2nd	3rd	TTL
Continue EDCD services while on wait list		1	1	2
Continue respite, companion, in home supports				
Continue and expand consumer directed services				
Continue choice in case management (like on DD Waiver)	1			1
Continue day support services	3	1		4
Keep array of services, just add more	1			1
Increase crisis services locally, overhaul emergency crisis system	10	2	5	17
Add residential option to DD Waiver	5	3	2	10
Add to array of services on ID and DD Waiver, including ABA	3	1	2	6
Need easier access to medical care including dental and specialized medical	7	3	3	13
Increase rates paid to people who provide supports (direct support, providers)	2	7	6	15
Increase how families know what is available, whom to trust, what is quality	7	2	3	12
Need better trained case managers	3	2	6	11
More flexibility/customizations in housing options so people live where they want	1	7	7	15
Increase services for families/family support, especially when family is no longer able to provide support	2	1		3
Make sure all individuals have advocates who are looking out for their best interest		2	3	5
Increase access to faith-based services				
Increase community capacity and funding for legal services			2	2
Increase rates to cover overnight and support for residential	4	3	5	12
Increase accessible housing for people	2	2	3	7
Increase capacity of community to support all people, including those with complex behaviors		2	3	5
Don't close all training centers	3	8	4	15
Increase bridge payments to provider who have individual who go into medical care/hospital		1		1
Increase information to community, law enforcement, on how to best support people with disabilities				
Offer true person centered services	3	2	1	6
Increase behavioral supports and qualified staff	2	5	3	10
More training for parents on assistive technology (how that connects to family life, assessments)	1	2		3
	1			1

Topic: Costs, Rates & Funding

Costs, Rates & Funding Comments	1 st	2 nd	3 rd	TTL
Continue day support services	6	3	1	10
Fund nighttime supervision in sponsored residential setting				
Pay all day even if client only there part day	1	2		3
Need process and documentation that is user friendly to stop 'pay back' issue	3	4	3	10
Funding for high medical supports to support community living		2	3	5
Make paperwork less cumbersome (person centered process causes some cumbersome)	2	1	3	6
Allowance needed for hospitalization/time away funding for in home medical care		3	4	7
Need new standardized tool for service plan based on need (not SIS)	7	8	5	20
Include adjustments for cost of living		3	3	6
SIS too subjective and left up to interpretation	1	3	1	5
Pay attention to quality of day support that is personalized/individualized	4	4	3	11
ISARS approval process needs sanctions, needs to be timely and consistent		6	4	10
Raises in rate structure	21	5	3	29
Include general supervision in congregate and in home residential services	2	3	4	9
Awake staff/night supervision need pay in group homes	1	5	5	11
Rates and cost need to compete with honoring choice			3	3
Medicaid transportation need funding for quality vehicles, to be timely	3	2	9	14
Use tiered bands with rates and budgets	2	4	3	9

Location: Lynchburg
Session: 6:00 – 8:00 p.m. Sept. 25, 2013

HOPES FOR FUTURE OF WAIVERS

- Support for more job and job search; supports to allow us to marry and live together.
- To be fair between all disabilities; the services and benefits need to be the same; a disability is a disability, no matter the type.
- Reach more individuals on the waiting list or eliminate the waiting list; Virginia ranks as one of the least served states in the country.
- Better funding for day services to be state of art; partnered with jobs and funding for job search.
- That the individual will be able to choose living in the community and participating in activities that they love and be given the opportunity to reach their potential.
- For individuals with ID to truly have an opportunity for a normal life.
- Provide for my child when I am gone – Medicaid?
- That the DD waiver is available for younger children when services can do the most good with social, language and physical therapy. A person can stay on the waiver no matter what the income will be. This is because young person starting out will not have the money to pay for help and support. Help for the high function person. The waiver seems to be designed for low functioning person.
- Want supports to move from group home to apartment.
- Increased waiver rates.
- Dental, transportation, workshops stay open.
- Important to live with my friends.
- To TSE equal between ID/DD waivers
- I hope the waiver will support people fully.
- Have more staff to help do things.
- That the services would continue of funding for all persons.
- Work toward providing waiver slots for all people with special needs.
- God would bless me with a lot of money live good.
- Hopes for waiver services that the plans take into account that the only way to address quality of life is by providing the adequately trained and paid staff. These are the folks who have “hands on” – very important – if not most important job.
- Bathtub in addition to a shower; new van; realistic financially for 4 person home with private bedrooms, training, get more out of my services; more focus on “me” being person-centered.
- I hope we can offer more choices of where they want to live;
- 1 comprehensive system which adequately funds inclusive, community services and with rate structures which encourage supported employment, having a home of your own, contribution and relationships. System promotes authority over the services received, including individual budgets.

TOPIC: Access and Planning

Access & Planning Comments	1st	2nd	3rd	TTL
Continue person-centered training to help people develop person-centered plans		1	1	2
Have people available to help people navigate the systems, like a case manager	1		2	3
Separate case management from service delivery	1	2		3
Have a single point into Waivers for all disabilities	6	3		9
Inform families earlier about Waivers, when they receive EI services	1	1	1	3
Increase information about Waives in rural areas, mass communication about Waivers everywhere, educate whole community	1	3	2	6
Decrease case load sizes		1	1	2
Need more equity and support for everyone	1			1
Increase focus on individual rights, more say over your money	5	2		7
Increase individualized focus of Waivers	2	2	5	9
Change eligibility process and tools (current tools not effective)			1	1
Do away with waitlist				
Increase capacity of providers to afford for more choice	1	1	3	5
More information for families that is comprehensive and a single point of entry/one stop		1		1
Reassess financial eligibility requirements				
How do people learn about out of the box services, increase those options		1	1	2
More electronic resources for individuals to learn about services				
Increase funding to allow more person-centered approaches	1	2		3
Schools needs to learn more about Waivers, give more information to families		1		1
Increase services for those with less support needs				

TOPIC: Service Delivery

Service Delivery Comments	1st	2nd	3rd	TTL
Continue some form of crisis support				
Keep consumer-directed services	1			1
Increase sponsored residential placements where can be the provider of services (ID Waiver)				

Service Delivery Comments	1st	2nd	3rd	TTL
Continue day support and pre-vocational services				
Continue transportation as a service				
One Waiver where all services are clear to people and families	3	2		5
Have one clear set of rules for what is eligible to be paid for		2		2
Have a single point of entry for knowing what is available for services			3	3
Improve quality and availability of behavioral support services/crisis support	1	1	3	5
Decrease turnover by paying staff better, turnover affects quality	1	1	4	6
Dental coverage for adults	4	3	2	9
Regulations need to support real lives, be more flexible to work in real life situations				
Waiver needs to support individual rights		1	1	2
Increase services that can be consumer directed	1	1	1	3
Services need to be more equitable in the Waivers	1	2		3
Broaden eligibility to include those with less support needs, they fall through cracks			1	1
increase eligibility of crisis services for people solely with an ID label				
Reevaluate policy that providers do not get paid when someone accesses consumer directed respite	4	1	2	7
Increase services (social skills) for young adults		1		1
Need residential options for DD Waiver			1	1
Vision services should be available		1		1
Better quality day support is needed, people need more individualized support, it is too much like institutionalized warehousing				
30 day visits by service coordinators (DD Waiver) is excessive, need less oversight			2	2
Medical support is lacking	1			1
Need more opportunities for people to earn a wage, a paycheck		3	1	4
More options to live independently	1	1	2	4
Raise level of respect/professional recognition for direct support providers through more training, higher wages	1		1	2
Increase nursing support in group homes			1	1
Overhaul day support services, day support-prevoc-community employment should all work together	1	1		2
Rates need to cover infrastructure	1			1
More options needed to allow people to be a part of the community, independent		3		3

Service Delivery Comments	1st	2nd	3rd	TTL
Services should not be dependent upon a crisis				

Topic: Costs, Rates & Funding

Costs, Rates & Funding Comments	1st	2nd	3rd	TTL
Fund environmental modifications and assistive technology	2		1	3
Increase incentives for employers to hire people with disabilities		1	1	2
Reevaluate billable hour requirements for providers, they need to pay for general supervision	4	2	2	8
Increase funding for intensive medical support				
Review appeals process for funded services/accommodations		1	1	2
Increase rates to attract more supported employment providers	4	2	1	7
Rate structure doesn't cover home or vehicle maintenance	3	2	3	8
Increase funding for crisis services	3	1		4
Need more state General Funds to help support services	2	1	3	6
More transparency on how providers handle individual's support				
Need livable wage for people in pre-vocational services				
Individuals income shouldn't impact SSI, disincentive to work	2	2		4
Allow providers to bill for overnight				
Use individual budgets	2	4	2	8
Transparency in funding		1	3	4
Funding should incentivize individualized, integrated supports	1	2		3
Cost savings should go back into system	1		1	2

Location: Manassas
Session: 3:00 – 5:00 p.m. Oct. 9, 2013

HOPES FOR FUTURE OF WAIVERS

- Have just relocated back to Virginia from another state – came to meetings to get information about current system and changes being considered
- Waivers address all disabilities that provide for all needs
- Matching service delivery with closures of training centers
- All disabled in need will be able to live as normal a life as possible without fear of cost
- Quality of life resources available – safety, activity, health
- Getting the word out to people at a young age – parents are not told
- A good life for me
- Overnight funding (1-2 hrs.) per person who has no unsupervised time in Congregate Residential – Person-Centered Planning
- No waiting lists; reconsider and expand work of Market Basis adjustments – choices should drive system
- Reduce/eliminate the wait, with fair determination who gets one
- That adequate funding is available for each waiver recipient to meet their service needs
- Improve the system of supports: by helping communities become more robust for services and supports.
- Waiver services need to be available to all and cover all needs of an individual and need to be fluid.
- That all individuals that need waiver services will get the services they need provided for them
- Increase the number of waivers for people eligible for service
- Easy and quickly accessed
- Wider services – behavioral one on one support; paid training for attendant/behavioral caregivers; 24/7 paid caregivers – so can live independent of family home
- Funding needed services
- Everyone who needs a waiver has access to a waiver that meets their needs
- Waiver for DD/Autism – more hands on for therapeutic consultation; respite/crisis congregate for kids
- Work towards identifying providers who can serve individuals with significant medical and behavioral needs
- It's available for all individuals with any type of disability with no limitations
- Adequate Northern Virginia funding
- My hopes for waiver services is that there will be more effort in decreasing the waiting list for those individuals that need support immediately
- Vocational programs for Autism. If one doesn't accept them, then find one that does.
- Waiver fully funds the supports that are needed where the person lives; funded is allocated for all – not just a few urgent; services are developed for various needs

- Quality of services and providers who are qualified willing and able to serve individuals with high medical and behavioral needs
- That everyone gets the same services no matter if DD or ID – should be one waiver whether you are born with disability, you will die with one – so the process needs to be fixed now
- Increased funding for those with complex medical/behavior needs; access to accessible housing for long-term living; dental coverage; more psychiatric services/practitioners
- More local providers for OT, PT, and speech; less waiting list time for people waiting for waiver slots
- Develop a spectrum of services with funding to access services until the outcome is achieved
- No waiting list for services
- Increased accessibility to waiver services so there will be no urgent wait list
- I would like to see the waiver supplement more families and provide funding for more person centered care
- A satisfying and safe life for my son away from home in the community
- One waiver that supports the individual with adequate funds to support that individual in the community
- That the right supports, at the right time, provided by experienced, skilled professionals are available to individuals so they can take advantage of life in their communities
- Services can be varied, more diversity in choice and model of service
- Eliminate slots – fund people and outcomes
- That everyone gets services they need and deserve
- Provide funding for all who need services
- I hope people would not be on the waiting list for a long time
- All individuals will be more into group homes
- That people requiring intense medical conditions will be provided with 24/7 support so they can enjoy life like those with lesser disabilities
- Common sense administrative reforms will be identified and implemented to reduce the administrative burden statewide through de-regulation “paper reduction” technological advancements, etc. The savings would go to direct support.
- Regulations don’t create unnecessary demands and limit supports
- Clarification of DD eligibility – where does it stop on the spectrum
- That all individuals have a life like yours and not have to be short changed because of budget
- Our child clearly needs a waiver eventually, however, he does not qualify at present time
- More funds
- That they are increased to include those not eligible for waiver today; LOF testing does not address all mental disabilities, to include judgment, etc.
- Eliminate wait list; keep the best of current waiver services and add a few more to enhance the system; have true crisis services across the state
- Going out from/with group home
- That they will be accessible to all and that everyone who needs it will get
- More available funds
- All are able to be served
- My hopes for waiver services is that every person that qualifies for these services are granted them at the earliest possible time of their life.

- Not limited to IDD, but include DDD to qualify without serving need. \Serve people in Northern Virginia equitably, with the rest of the state – provide realistic cost differential
 - Hope that the opportunity is open to more families in need; hope that the service is better funded
 - I hope that my son who is on the DD waiver will have residential funding and support
 - Providers of services will be paid at competitive rates for region
 - Less unfunded mandates or fairer coordinating unfunded mandates to be more efficient across agencies and providers
 - Fairness to all; realistic rates; need/intensity – barely enough funds; simple as possible
 - More ID waiver slots – not to be combined with DD waiver
 - One comprehensive waiver that serves all disabilities (including brain injury). This waiver should allow for person-centered needs/wants assessments that generate a flexible budget which individuals can use in and out of Medicaid to purchase services and supports that allow them to be independent and involved community members.
 - Develop increased day supports and supported employment
 - That it covers all of the special needs – all levels; make all people available for services
 - That all those with disabilities are served
 - To continue and provide the appropriate funds to provide equality service for individuals with ID
 - No waiting list for waiver that supports person-centered plans
 - Individual budgets while rational are dangerous unless assessments are independently validated
 - One comprehensive system that ensures access to individualized supports whenever needed
 - Waiver services should be based on needs – not arbitrary definitions like “IQ below 70”. Adopted son with Fetal Alcohol Brain Injury needs services (broad range) but none are available
 - Make sure those individuals that have complex medical and behavioral needs are funded adequately so that the providers of support have the ability to properly care for them. There are the right team members for both professionally, paraprofessional and family
 - We find a way to serve those who need if
-
- The waiver should emphasize supports over paperwork and rates should reflect real cost to provide that service.
 - Cover dental in the same way health is covered. Otherwise care is not holistic and person-centered.
 - I hope they are complete enough so that people with intellectual disabilities are not able to just answer they are “fine” and be left out.
 - Both DD & ID can receive same level of quality services, that these people don’t have to be on a waiting list for years
 - Easy access and more funding
 - Easier access to waiver funding
 - That they are easier to access
 - Cost of living raise for waiver reimbursement
 - Availability of wheelchair ramp
 - Waiver money for wheelchair, canes, technical access homes
 - My wheelchair limits the group homes I can live in
 - People with brain injury qualify for a waiver should have needs equally considered regardless of age (ex. – past 22)
 - Jobs availability with my waiver
 - Truly person-centered services available to all Virginians with ID

- Make available to more people; let more people know they exist!
- That we will be able to create supports for my daughter (with ID) so she will be able to live a life customized for her (instead of just accepting “what is”)
- Adequate funding for individuals with complex needs; more flexibility in the services the waivers offer
- Shorter time on waiting list
- To see waivers combined and think EDCD waiver is great, but so many people using that waiver when they really want DD or ID waiver
- Shorten the list
- More funding
- Set waiver rates based on true cost of supporting people in the community
- Adjustment for rate structure for ICFs of 8 people
- An efficient, flexible system that enables individuals with disabilities to access supports throughout their life span that responds to changing needs, adult intake, self-direction, access for those requiring fewer supports
- More allocated funds to serve more individuals
- Provide community-based services at all need levels
- Hope rates go up so providers can invest back into employee salaries/benefits
- Provide intensive and appropriate support for people with severe behaviors
- Everyone who needs a waiver can receive one without waiting list
- I hope these will be a cost differential for Northern Virginia
- More people can get waivers and have access to services without long waiting lists
- No waiting list
- Virginia, for the first time, will become nationwide mecca for best practices in delivering I/DD services and supports
- Close institutions; provide appropriate living arrangements for individuals; provide day support, job supports, and transportation; provide necessary community supports
- More slots and one comprehensive waiver based on someone’s needs, not diagnosis with equal rates and higher rates for services, and a faster authorization process
- I think is very idea bring people to community instead institutions and will allow more need people get in the waiver
- Waiver dollars are sufficient to support people to have the best life ever
- Services and providers that actually provided the supports they say they will provide
- Supports and services for everyone in need – no wait lists!
- A more smoothly and efficiently delivered waiver that encompasses services and therapies people need to use
- No wait list – more transition supports
- Rates cover the services provided to individuals with DD/ID
- All those in need are covered (funded) at least insofar as to insure that their most essential (housing, shelter) and health needs are met
- Serve people based on need, not dx. Include people who don’t currently meet criteria but meet the needs (TBI, strokes). Increase rates for providers to ensure availability of quality of services
- To support need individuals in the community
- Arrange for a website for voluntary services, contributions, and scheduling with clients; independent living services community activity opportunities
- We find a way to serve those who need it serve; the process is too long

TOPIC: Access and Planning

Access & Planning Comments	1st	2nd	3rd	TTL
CSBs and schools need to meet to identify needs				
Private vendors to do education and outreach		1		1
Continue respite, day support and adult services	5	4	5	14
Continue to have choice of services and providers, enough viable options to create real services		1	4	5
Continue person-centered concepts		1	2	3
Keep vocational and day time options	3	5	2	10
Continue and expand family/caregiver training	1	1	2	4
Fund people not Waiver eligible				
Outreach to jails to find eligible individuals, outreach to all public servants	2		1	3
Clarify when family members can be service providers				
Eliminate need to repeatedly re-justify services				
Keep more than one training center open	2		1	3
increase regional analysis and planning based on need				
Need a system that accommodates people of all different levels of need				
Better communication between public/private schools		1	1	2
Increase statewide level of functioning training	2		2	4
Change level of functioning, clarify criteria		1	5	6
Educate families and CSBs on eligibility		5	1	6
Get rid of level of functioning terms and move to needs/support assessment system	8			8
Eliminate wait lists		2	2	4
Wait list system should account for needs and wait time	2	1		3
Educate/outreach to families/educators/health care providers to get families linked to system asap		4		4
Standardize intra and inter agency protocols and clearly follow them (CSBs, DSS, Health)		1	1	2
Change Waiver to community 1 st terminology			2	2
Adjust eligibility to focus more on independent safety and decision making, no IQ focus, include adult on-set brain injury	10	2	1	13
Need better system to notify people of IFSP and other resources	1	1		2
Forecast needs and services to plan and eliminate wait lists	1	5	8	11

Limit repeated eligibility evaluations to maintain services, get away from need for traditional psychological evaluation for eligibility	1		1	2
Eliminate eligibility silos for diagnosis			1	1
Need central, comprehensive information and referral source	2			2
Need more flexible service system driven by needs	13	9	6	28
Don't have people tied to Medicaid or specific providers to access services			1	1
Build provider capacity	2	10	5	17

TOPIC: Service Delivery

Service Delivery Comments	1st	2nd	3rd	TTL
Continue services people are currently getting	1		1	2
Continue consumer-direction	1	4		5
Offer both consumer and agency directed services			2	2
Keep housing options and expand them to DD Waiver			2	2
Allow people to use non-disability related services				
Increase networking with employers			2	2
Dental care for adults	1	2	1	4
Increase funding for START crisis services and expand to children and other disabilities			1	1
Increase network of volunteers to support people				
Eliminate '457' plan to align DD plans with ID format (person-centered planning)				
Add behavioral supports to Day Support Waiver		3	1	4
A provider change does not necessarily mean a need for pre-authorization				
Fund personal attendant services while person hospitalized		2	1	3
Services should be based on need, not label	6	4	5	15
Increase livable wages/rates so more qualified attendants/providers are available	1		1	2
More flexibility to accommodate people as they age	1			1
Support and education for people maintain jobs/employment	1	3		4
Increase community activities	2	2	1	5
Better transportation accountability		4	2	6

Service Delivery Comments	1st	2nd	3rd	TTL
Decrease double billing		1		1
Increase neurobehavioral, crisis supports for people not on Waiver, falling through cracks	1	3	2	6
Increase competency, quality of providers	2	4	3	9
Increase communication between schools and DBHDS				
Increase crisis supports for people who are non-verbal		1	3	4
Redefine eligibility not on IQ but based on new science	2	1	1	4
Increase supported employment	5	3	2	10
Set standards on person-centered planning, not institutional criteria			2	2
Support individuals with aging family caregivers so they have access to services before crisis	6	1	3	10
Support finding, keeping, training providers/caregivers	2	5	6	13
Intensive medical supports (nursing 24/7)	2		1	3
Need accessible homes (ramps)	3	1	5	9
Improve fiscal agent (KeyPro, PPL, IDOLS) prior authorization process and timelines (to 2 weeks)	1	3	2	6
Make individual budgeting available	1	6	3	10
One Waiver	15	5	1	21
Increase accurate information so people can find services that match their individual needs	1	2	2	5
Increase supports at home	1	1	1	3
Need effective case management for navigation			2	2

Topic: Costs, Rates & Funding

Costs, Rates & Funding Comments	1st	2nd	3rd	TTL
Continue funding for ramps, access to environmental modifications, and assistance technology	1	2	2	5
Make funds available for universal design in housing	3			3
Maintain consumer-directed services for personal attendants		5	1	6
Funding for day services and keeping people at home	7	3	1	11
Use technology to bring down costs		1	1	2
Residential providers need to bill for EM (?)	2		2	4
Adjust rates up to increase hours of respite back to 720	5	4		9

Costs, Rates & Funding Comments	1st	2nd	3rd	TTL
In Northern VA, increase funding or all services to be consistent with 'market basket'	4	4	5	13
Align expenditures with rates	2		1	3
Speed up invoice process	3	1		4
Align rates with expectations, consistent with retro pay	6	7	3	16
Align rates to CPI index (?)		1	2	3
Fund one-on-one supports		2	1	3
Vary rate depending on person's needs	7	5	6	18
Align services based on needs, if Medicaid service or not	1	2	4	7
Have objectivity with approvals for environmental modifications and assistive technology		3	2	5
Allow billing for overnight and general supervision	8	9	3	20
Overnight supervision for those who want to live alone or with a friend, not in congregate			1	1
Need housing modifications so people can use bidders outside Medicaid	2	1		3
Increase funding for employment	2	3	5	10
Help people with low income afford wheelchairs	1		1	2
Need higher, livable wages/rates for direct staff	17	6	12	35
Providers need medical benefits		1		1
Should get paid for employment supports and personal assistance at same time		1	2	3

Location: Manassas
Session: 6:00 – 8:00 p.m. Oct. 9, 2013

HOPES FOR FUTURE OF WAIVERS

- More serving for those on the DD waiver – behavioral, adult day support, housing
- Greater emphasis on one to one activities and interests – higher rates for this
- Include group house for all the waivers
- Combined ID/DD waivers
- That better transportation service is available or there are choices! Logisticare not governed enough
- I hope that I can get an ID waiver and I can get help living independently and also get one of the waivers

- That more services are covered under the waiver, like therapies
- Decent pay! Living wage
- To include inclusion in the community and acceptance
- Efficient, effective, accessible
- I hope that the waiver allows for my family member to live closer to home. He is 3 hours from home.
- Services for all!
- More accessible better funding for providers to offer more supports to individuals who are in need of more support
- They will be more focused on quality of life
- Flexibility within the waiver!
- I would hope that therapy and adaptive equipment for my daughter would be covered as well as counseling for the family
- Hope things get better through the years; things still need change
- No waiting list; more coordinated services; more public input
- More restaurants and Captain Ds in Woodbridge, places to go; need another Spirawels – job program
- Employment options!
- Better staffing and trainings
- My hope is that the waiver services will work effectively to focus on the best interest of my son
- Higher hourly rates paid to respite providers to increase quality of care
- Help there is housing
- More service options specific to the individual's needs; decreases wait time for ID waiver – we have been waiting 1 year – average time is 7-10 years
- That there's really enough money to pay for housing, transportation and "life" supports, i.e., PAs

- Hope for flexibility so that where my daughter's needs change, her services will be able to change with her.
- To continue to receive the care we need and to be able to find more qualified care givers
- Access to services promised!
- Why don't I have enough interpreter everyday without any sign language interpreter? That's not fair.
- That the qualifications be clearly defined and the waiver information reach those in need. If the IQ level is 70, don't float it!
- I am hoping that an effective system is in place so when I pass, he will be served
- I need an interpreter
- Better education of general public about I/DD and more community inclusion
- A way to find out whether the waiver application is approved instead of waiting for it in the mail
- Availability for my son so he can live in a group home – have his own life
- I hope waivers and the processes to attain them and the case to work within them foster a high standard of services
- To be managed wisely according to biblical principles so they may continue long-term
- To be able to have enough waivers for all people that are eligible for them with no waiting list
- Lessen the time waiting for approval of waiver
- Less rigid system; greater focus on individualized services, more slots available
- That everyone who needs services would receive them
- I hope my son (who has been on the ID waiver list for 8 years) can actually benefit from having a waiver and receive appropriate supports for employment and independent living.
- One process, one criteria

- Fair reimbursement for services so there are more providers
- Implement current technology to better support communications services in all settings
- Hope for some sort of long term investments maybe partially funded by the state – similar to long term care or the college savings fund of the state.
- Pay more to providers for medically sensitive clients
- To have more services for handicapped people in PWC
- Need financial as well as technical instruments to support my son
- Supports for people with disabilities to stay at home or on their own, not just for x amount of hours a week, but overnight or to assist each morning, etc.
- A variety of services across the lifespan to meet needs as they change
- Smoother access to information and better communication for waiver
- To have more services for deaf and MR handicapped people
- Competence!!
- Focus on providing more individuals some help versus a few, a lot of help
- That more waivers are available so the wait list is not so long
- More houses and help
- Why doesn't the Partnership include the Board of Education? The Board of Education is not preparing students who will probably receive ID/DD waivers.
- I hope my son can have an aide/companion to help him with schooling/independent living /and employment
- That the waiver process would be easier to understand
- That personal attendants would be paid more money per hour.
- Flexibility – low bureaucratic overhead, efficiency; consideration of changes throughout lifespan; well

integrated with other service systems (schools, DRS, justice, etc.); leverage and support natural supports

- I wish I had an interpreter everyday and forever! Just for my job club
- Services needed for those rejected from waiver
- Support my son to raise him and develop intellectual abilities; need medical support
- Hopefully future waiver services are more easily understood than currently.
- I hope future waiver services are both available and attainable.
- My hope is for the waiting list to move forward. Our family members wait for years to receive services.

TOPIC: Access and Planning

Access & Planning Comments	1st	2nd	3rd	TTL
Continue day support and vocational services, access sooner because there is a Day Support Waiver				
Have VA Dept of Deaf/Hard of Hearing link to disability services system, outreach to school deaf/blind				
Increase outreach to parents, schools, MH providers	11	2	3	16
Provide clear information on Waivers, how to apply, use, navigate	2	4	4	10
Ensure consistency of information, agencies, applications, providers			3	3
Training for families on navigating entire system	1	1	1	3
More contact information, resources to people on wait lists			4	4
Shorten wait lists to ensure early intervention and prevent crisis	4	1	2	7
Centralize intake system		1		1
Limit focus on IQ and ID vs DD – just one system for all diagnosis		2		2
Make easier access to assessments and eligibility documentation	1			1
Better communication between groups (schools, CSBs, state agency)	2	3	1	6
More case managers/service coordinators, particularly areas in rural, underserved areas so there is real choice				
Consistency in case management across CSBs		1		1
All providers trained to work with a range of disabilities				
One comprehensive Waiver with universal service menu	5	10	5	20
Service coordination between schools and adult services	2	3	4	9
Increased support focus on independent skill development designed to encourage choice	2	1		3
Have enough available service providers, flexibility with finding providers outside existing list of approved DMAS providers	2	2	2	6
Streamline provider process for becoming an approved providers	1			1
Wait list that takes into account time spent waiting				
Limits on financial eligibility are too strict				
More clarity to families on wait list on when services will be available				
			2	2

TOPIC: Service Delivery

Service Delivery Comments	1st	2nd	3rd	TTL
Personal development for people with I/DD				
Volunteer opportunities for people with I/DD				
Efficient and effective approval for new providers		1	4	5
Increase provider pool in Northern VA	1	2		3
Continue consumer-directed services	2		1	3
Continue community inclusion		1	1	2
Continue transportation services			4	4
Improve criteria for people with I/DD who are deaf, language and literacy barriers		1	1	2
Better coordination for kids – adult transition of Waiver services	3	1	1	5
State criteria for procurement that includes employers of people with disabilities, meaningful employment for people with disabilities	1	3	1	5
Pool Waiver services for the Deaf to promote and encourage ASL among community	4	2		6
Increase medical in-home services/hours based on need	2	1		3
Support people at home to do what they want to do, not what we want them to do				
Create day and residential programs for ID and behavioral support	4	1	4	9
Livable wages for direct support providers, benefits and holiday pay, differential for Northern VA				
Day support programs pooled for ASL and I/DD built into Waiver	4	2	1	7
Develop training programs for providers on ASL				
Higher rates for Northern VA	1	2	2	5
DD Waiver needs congregate support	1			1
Increase adult day supports and behavioral/crisis services	5	4	3	12
Provide current, accurate information and resources on services	1			1
Support and funding for intensive medical services	1	1		2
Timely response to calls				
Increase and improve awareness in high schools, college, etc. of need for direct support staff as a career			2	2
Need continuity and uniformity across counties and the state in Waiver		2		2
Flexible in-home supports		1	2	3
Mainstream technology, no 3 rd party system, get rid of extra expenses	1	2	2	4
Allow multiple providers serving at one time	3	2	3	8

Service Delivery Comments	1st	2nd	3rd	TTL
Better coordination, cooperation and understanding between support staff	3		1	4

Topic: Costs, Rates & Funding

Costs, Rates & Funding Comments	1st	2nd	3rd	TTL
Maintain Northern VA differential	9	2	3	14
Increase OBRA funds used for non-waiver eligible people so they can get out of nursing homes	3		1	4
Keep choice and competition in DD Waiver		1		1
Keep funding community activities	1	2	1	4
Keep funding for services			3	3
Keep consumer-directed services, hire competent people	1	2		3
Maintain current services			2	2
Funds things like a vehicle on behalf of people with disabilities who don't drive	1	4	2	7
Decrease administrative burden, use technology better, less complex, more user friendly		1		1
Add individual budgeting, middle men drive up cost		1		1
Increase wheelchair accessible housing				
Use a lifetime cap on environmental modifications (instead of annual cap) with an easier process to use				
Increase staff pay			2	2
People with disabilities need jobs and more money				
Providers/professionals should have influence on regulations, forms, tools, etc.		2		2
Ensure quality staff through better screening processes				
Increase transportation providers by opening competition				
Increase rates and capacity of doctors who take Medicaid				
Create a means to intervene for crisis services, not preventative				
Open up EPSDT services to those on wait list				
Rates should match the real cost of services	3	4	6	13
Need affordable rent	1		1	2
Offer choice and competition in ID Waiver				
Close institutions				

Costs, Rates & Funding Comments	1st	2nd	3rd	TTL
Align rates in DD Waiver with ID Waiver particularly case management/service coordination, work people, not paper	8	1	4	13
Include group homes in DD Waiver	3	2	3	8
Use a multi-tiered system based on individual needs and size of program	2	2		4
Give supports people need, flexibility, go where I want, be a 'rolling stone'	1	3		4
Have a savings plan like college savings plan that families can put money into for the person's future needs	2		1	3
Increase accountability and transparency around whole system, particularly transportation (logisticare)	2	6		8
Make results of state monitoring public so people can judge which service/providers are best			1	1
Increase medical services and rates (acute care)		1	1	2
Cover dental for adults				

Location: Norfolk
Session: 3:00 – 5:00 p.m. Oct. 2, 2013

HOPES FOR FUTURE OF WAIVERS

- Service delivery can be “tailor-made” to fit the needs of my child instead of “fitting into this waiver box, or that waiver box.”
- Being person-led real options about what services could look like; “interviews” with providers; plan documents that follow people so . . .
- My hope is that waiver services are used in the best possible way for the consumers who need the services.
- Those that need the waiver can access and receive it right away without being on a waiting list for years.
- All individuals who need services/supports can get them without having to wait years; supports at correct level for individual; better way to monitor when it is needed or if it is needed.
- Eliminate the requirement to obtain/rule out an ID diagnosis for the new waiver. DD diagnosis should be enough.
- Eliminate waitlist, streamline service delivery; replace Logisticare with efficient provider.
- Helping people with disability through services. Karla Gattling
- Documentation should be uniform across the state. It would be much easier for providers as well as reviewers if the documentation is consistent.

- I want to have confidence in the process of obtaining waivers for my son that when I and my wife are gone that my son will be taken care of in my home.
- Individual access to services, not grouped; decide now to use funding.
- Preferences/supports/best practices; don't get lost in the shuffle; approve AT/EM.
- That every individual who needs the waiver services receives them; that waiver services will provide adequate supports for individuals to live and work in the community.
- Plan for retaining PCAs?
- I would like to see the waivers be consistent and fair to all.
- Services should be about the person, not the system; waiver should be about the person, not the system.
- Better access to referrals.
- My son has the ID waiver. He has had the MR then ID waiver for 13 years. It has been a lifesaver for our family and has made a huge difference in his life. He just transitioned to a day program. I do not want to lose any supports.
- Distinction between diagnoses are eliminated for eligibility purposes, and everyone that needs services have an equal opportunity to receive them.
- More people getting slots choice in all services including case management; more consumer-directed services and higher pay rate for CD.
- People's waiver slots allocated by who has been on the list the longest.
- Everyone who needs supports can get quality services delivered in a timely fashion and have a choice of where these services are to be delivered
- My hope for the future of waiver services appears as if it will be addressed and that is having individuals that have

the need but they do not have the waiver to assist them in having their needs met.

- PCA training similar to Virginia Caregiver (They use Easter Seals training.).
- DD waiver services for adults? Real employment?
- Assist with hiring, managing, caregivers
- Hope waiver system services will allow more activity based training.
- They are expanded to move to reduce waiting list; flexible so caregivers/recipients can make choices with a lot of restrictions; that they will be there for a lifetime.
- All waivers in one umbrella!
- For everyone that needs a waiver to get a waiver!
- Military families need to be able to transfer into Virginia with waivers from other states
- Plans for individuals are not copied and pasted for the approval of hours, but actually outcomes that the individual wants/needs.
- My hope is that the funding for services not be caught up in bureaucracy and easily there as need. How are we avoiding red tape?
- On DD waiver my son can own and live in his own home? Not in a group setting.
- PCA benefits, health (insurance, dental, sick leave).
- No stipulations on behavioral consultant services; ability to have providers bill for all contacts made on person's behalf.
- Higher pay rates in Hampton Roads region.
- For services to be the right fit for person in need.
- Adequate rates to serve all individuals to include these with medical needs; blended system with CSB in the central point of entry.
- No more waiting list and full choice on how you use waiver.
- Provide services to all who need them; increase reimbursement rates; not based on SIS scores.

- My hopes for the waiver service all that the process for assessment regarding ID are revised.
- That the SIS fact sheet not be the sale too – to determine an individual with ID’s needs; that a family’s needs of an individual with ID be considered.
- To have places they can go for fun.
- Housing separate from support.
- That they be easily accessible. Families don’t have to jump through hoops. There be one waiver that simply meets your unique needs.
- I hope that my daughter will be able to work and live in our community with the supports that she needs. That the waiver will help provide these services in an organized and timely manner.
- Access to all individuals on the list. Eliminate the long DD wait list, 7 years. Streamline the process so it is user friendly. Folks get lost and give up. Providers need to be more competitive in order to ensure sticking around rather than funding other jobs. More public outreach and training for families. Earlier notifications.
- For all individuals with DD or ID to live in their community with proper supports – A Life Like Ours.
- To be available ASAP and not be on a wait list for so many years. Be able to pay my caregivers what they are due for all the work they do - \$10 or more per hour.
- To expand worldwide and educate people on different services they offer with a person with disabilities.
- That some type of reciprocity between states will exist for our military families required to move between states. They often lose their places on waiting lists and must start again.
- My hopes for waiver service are that it provides errant funding for community integration, target core funding for modifications for community living.
- All families in need of support will be able to access waiver services.
- Transportation, more job opportunities.
- Paid organized trainings for attendants working in family homes; easier process for obtaining assistive technology and environmental modifications for people supported with waiver; case management is a huge barrier.
- That all who need services could receive services.
- Don’t make a Z-tiered waiver (support waiver vs. comprehensive waiver). This will cause people to manipulate their plan to receive supports from waiver that is easier to obtain.
- Waiting list response is quicker and referrals are fair to providers.
- More slots to serve more individuals; more individualized service plans dependent upon needs of person; more transparent and organized systems; fair and equal screening process of screeners; more open communication process; more trainings of screeners.
- I hope all Virginians who need waiver services to remain in the community will receive them; people do not live in institutions.
- Rates to be adequate to cover the cost of providing services; an organization’s time to not be consumed with the documentation requirement of waiver services; more waivers available immediately; more community resources.

TOPIC: Access and Planning

Access & Planning Comments	1st	2nd	3rd	TTL
Keep Money Follows the Person slots				
Keep respite as a service		4	1	5
Keep emergency slots		1	1	2
Keep ID Waiver slot allocation as urgency based		5		5
Keep CSB as single point of entry (ID Waiver)	8	1	1	10
Maintain consumer-directed services	3		3	6
Keep provider list on DBHDS website			1	1
Survey Monkey database does not work –needs to be more person-centered				
Make family caregiving option across the board	1			1
Monitor quality of who is providing screening for EDCD Waiver (families are forced to file appeals when their child is eligible)		2	2	4
Increase number of waiver slots	8	5	5	18
Have more community resources across the board (rural and urban areas)	1	1	2	4
More independent living options	1	2	2	5
Better planning and process for adults who have a guardian		1	2	3
Access to better provider information and choice		1		1
Get information about Waivers as soon as child is diagnosed by doctor	6	6	3	15
Quicker access to Money Follows the Person funding and re-authorizations	1	1		2
Have the same process across the state for applying for and becoming eligible for Waiver (too confusing between ID, DD and EDCD waivers)	1	1	6	8
Not able to hire private case mgr, need choice	2	5		7
Case managers should not do screening and offer services, conflict of interest	6		1	7
Make emergency slots more accessible by better defining 'emergency'		2	3	5
SIS should not be the only assessment tool to get services, person-centered considerations	3	1	3	7
Need reliable administration of SIS across state, administrators				
Combine ID, DD and Day Support Waivers	3	1		4
Change regulations related to environmental modifications and assistive technology so easier to access and provide more funding for the services		1	3	4

TOPIC: Service Delivery

Service Delivery Comments	1st	2nd	3rd	TTL
Continue respite services	1	1	2	4
Continue and expand sponsored residential placements, advertise this service more	1			1
Increase and expand peer mentoring	1	3	2	6
Continue and expand vocational services so people can have better jobs, start in high school	2	1	1	4
Continue to allow consumer-directed services to be provided by the family	2	1		3
Continue choice		1		1
Continue to close training centers	1		1	2
SIS needs to be restructured to actually evaluate the needs of people, need a better tool and different process				
Need more crisis services, need to increase as there is limited capacity, its not timely enough, need more hours (30 or more a year is not enough – need 20 a month)	10	2	1	13
Decrease system reliance on group homes				
Increase training on how to hire and manage personal assistants	1	1		2
Need a more effective process for eligibility approval for ID/DD Waivers		2	1	3
Need more capable staff to work with people with complex medical issues and crisis needs, particularly those that are transitioning from training centers	1	3	4	8
Increase ICF ID service			1	1
Increase availability of transportation services		4	2	6
Increase numbers of skilled care facilities	1			1
Merge ID and DD Waivers	2	2	2	6
Need better options for employment and vocational support for youth graduating high school, not one size fits all	2	3	5	10
Need a fair referral system for in-home services	5		1	6
Make easier admission to training centers		1		1
State to state transfers are very difficult			2	2
Decrease reliance on guardians and authorized reps and increase supporting choice	2			2
Increase behaviorists, OT and ST providers	1			1
Increase housing vouchers				
Increase intensive home services		1		1

Service Delivery Comments	1st	2nd	3rd	TTL
Need new Dept of Human Rights		1		1
Need more training for personal attendants on disability issues				
Need an efficient intake process for supported employment		1		1
Institute a process for fraud when parents are paid	1			1
Increase employment opportunities in the community for livable, real wages	2	1		3
Revise assessment for medical and psychiatric needs regardless of ability to be independent	1			1
Increase attendant wages	1			1
Increase access to high quality medical and pharmacy services	1		1	2
Make available funds to train consumer-directed support workers			1	1
Expand options to support people living in small settings, in own home	2	7	4	13
Expand specialized medical and psychiatric providers			1	1

Topic: Costs, Rates & Funding

Costs, Rates & Funding Comments	1st	2nd	3rd	TTL
Keep environmental modifications				
Keep respite, a much needed service for families		3		3
Continue to deinstitutionalization and support to residents				
Maintain investment in case management (including training in outreach)		1		1
Providers and families are eating the cost of exceptional needs care		2		2
Funding for overnight supports insufficient		1	1	2
System promotes part time employment of providers causing staff turnover, low pay, people/families paying extra for services				
Transportation rates contracted to cabs are a higher rate		2	2	4
State level inefficiency – move money to community supports	1	1	2	4
Need dental funding over age 22	1			1
Decrease long wait lists	1		4	5
Rates for in-home services need to reflect quality of support staff needs	5	3	2	10
Allow units of service per month	1		4	5

Costs, Rates & Funding Comments	1st	2nd	3rd	TTL
Rates should be established based on quality of staff	2	2	3	7
Accelerate process for service authorizations	5	2	1	8
Establish a competitive reimbursement rate for attendants and therapy providers	6	3	1	10
Evaluations based on individual budgets		1	1	2
Evaluate respite hours to be cost effective, money lost because of flat number of annual hours	1	1	3	5
Get rid of 'no vacancy' factor for absences, attendant support cannot be paid for family or hospital stays	6	8	6	20
Need cost of living adjustment, overall low rates (ranked 47 th in nation for I/DD spending)	12	7	4	23
Need doesn't match what is billed		1	1	2

Location: Norfolk
Session: 6:00 – 8:00 p.m. Oct 2, 2013

HOPES FOR FUTURE OF WAIVERS

- To address the extensive wait list; to streamline the process for both ID/DD waivers – information is inconsistent even within the city; to see more outreach so that information is saturated into the community right at DX; to see an individual budget per individual for waivers - some families need more intensive than others.
- Adequate and competent support to help individuals with autism, and other disabilities, including higher functioning ASD, to have jobs and live independently in the community as happy involved citizens.
- That my child gets one (a waiver), and it provides him support to live outside of his parents' home with friends and gives him an opportunity to do productive things during the day like work or volunteer.
- More slots, more slots
- A rate structure that makes available as many financially viable residential and other services in both rural and urban settings.
- Not to be on a waiting list for 10 years.
- All school personnel need to have knowledge on Medicaid waivers to help identify families.
- Change age (all ages) limit for caregiver to live in the home for consumer directed.
- Rates will meet the needs of people who need more support; training for CD services – family, staff; appropriate day programs even for lower functioning people

- Support for my child to be able to go into community with _____ children for camps or activities – summer care.
- Waiver services to continue at current level, to be portable state to state and not have to go to bottom of the list if relocate
- My hope is to keep the sponsored residential services funded through waiver
- Stop paying stupid things like building a gated community for people with disabilities. I would like to join the City Council of Virginia Beach, VA.
- Waiver should prevent placement of children with ID outside the home and maintain the family until they are ready to leave the nest.
- No waiting lists.
- Easy access and use.
- People can access what they need when they need; it can meet a wide array of needs.
- There is a lot of a job ahead for waiver services to be successful. Bryant Richardson
- Need more accessible ABA therapy centers. Some of them have 6-8 months waiting list.
- To be able to receive a Medicaid waiver for my husband who suffered a traumatic brain injury this past April. It has been very difficult to find answers to my questions, and any support when talking with Social Security.
- Need a comprehensive list of school advocates for IEPs.
- That the waiting list is shortened
- More work and better services and more slots for Medicaid waivers.
- Accessible to individuals right after high school; coverage and access to more EPSPT services in a timely manner; parent support groups that are readily available
- System that supports clients as individuals and is responsive to their needs – crisis intervention
- To have viable and useable support sin place to enable my son to live and fully be a part of the community
- All persons needing a waiver would get one so that services are available to those who need them.
- Consolidate, simplify, and streamline process
- Some sort of support needed for siblings with other siblings and their disabilities, like _____ - CHILd has a group, but we need more!
- My hope is to see the wait list go down; to see that attendants are paid equally across the board; that the screening process is done fairly and unbiased
- Waiver services will become more available to those who need them, regardless of a set of criteria, and will be used to serve those individuals the way they want to be served.
- Better qualifying process; better communication of available services
- ABA therapy (BCBA supervised), medical and dental coverage, support for post-secondary education and job training, supported employment, companion support, integrated community housing (not segregated)
- Sufficient funding and appropriate reimbursement available to home and auto remodification
- If Early Intervention is “key” in many ways, why don’t we have services or waivers available for our children under 6 years without long wait lists?

- I cannot answer this question because I do not know about any of these waivers – never heard of them, therefore I know not what to ask
- I would like no wait list and a variety of services that can be offered at affordable costs. My oldest son is on the DD wait list, and my youngest is five and doesn't qualify.
- Better information to understand the waivers and who should apply
- Better living for people with disabilities; more wheelchair accessible housing
- People/children get services when they need it; wait list too long; special circumstances considered for children from single parent or other non-traditional homes
- Low pay and benefits in Hampton; RYs get unprofessional, unqualified employees
- That people who are waiting get on the waiver quickly
- Increase rates of reimbursement, employment opportunities, work experience, trained job coaches, increase provider
- More support for case management to have more administrative-like support so they can focus on programs instead of AT/EM approvals; respite needs to be more flexible based on individual needs; overnight support for sleep disturbed and wandering individuals; reduce the wait time for AT/EM approvals; cumbersome 2-year process in some cases
- For Bessie – she like the program she has; Tim likes the waiver that they have

TOPIC: Access and Planning

Access & Planning Comments	1st	2nd	3rd	TTL
Like Care Connection for Children (title V) services	1			1
Keep choice in consumer-directed services				
Keep respite	3		2	5
Like that letter of available funds is sent (DD Waiver)				
Project Lifesaver has Waiver information	2		1	3
Keep parents being able to be sponsored residential provider, provide more training on this	6	2	5	13
Keep ability to use family member (regardless of their age) in home as a provider	2	2	3	7
Use a rating system from consumer reviews that is public information		3	1	4
Use a rating system based on standards		1		1
Need family provider training, how families manage providers in their home		4	1	5
Increase advocacy for raising provider rates to attract more quality people	2	5	2	9
More provider training with requirement checklist		2	2	4
Provide training to individuals on services	1		2	3

Family have profile and plan of care training		2	1	3
Training on knowing what to expect during waiver screening	1	1	1	3
Make sure changes don't disqualify person on a wait list				
Make waivers portable across state lines	3		1	4
Increase number of case managers, caseloads too high	1	4	5	10
Need more than a 12 month review			1	1
Need more information about Waivers early on (EI, schools, DSS, etc.)	7	9		16
Un-complicate process for applying for waivers		2	2	4
Make sure Care Connection for Children aware and knowledgeable of Waivers				
No wait lists	9	1	2	12
Offer same services across Waivers				
Have same eligibility requirements across state, across Waivers			3	3
Provide service while on wait list	1	1	1	3
Consolidate waivers and base it on need	2		3	5
Increase attendant hours across services				
More training for services facilitators		1	1	2
Have checklist to prove information was provided to families				
Fund more slots	5	4	2	11
Better process for how slots are determined				

TOPIC: Service Delivery

Service Delivery Comments	1st	2nd	3rd	TTL
Need day support options for people to go in community		1	1	2
Continue quality residential supports	4	1		5
Continue quality medical supports	1			1
Continue supported living where people can be independent, especially those currently living with elderly parents and moving out	4	1	1	6
Continue sponsored residential with appropriate supports in place to be successful, people should be allowed to stay with family who can be paid as a residential provider	2	3	2	7

Service Delivery Comments	1st	2nd	3rd	TTL
Continue choice in providers				
Create more incentives for qualified providers to work with the surge of people accessing services through DOJ	6	2	2	10
Make crisis services more responsive, accessible to prevent crisis	2	4	4	10
Increase benefits and living wages for providers	3	2	6	11
Increase sponsored residential placement and make it first choice rather than last resort	3			3
Case managers and support staff need to be better trained and versatile between MH, employment, ID services, etc		6	1	7
Have consumer-directed option for in home services (DD Waiver)	5	3	6	14
More information available to families on options, have a single point of entry for all waivers			3	3
More divers options for job coaching, job development that are individualized and based on person's needs	1	2		3
ABA needs to be added for adults	4	4	1	9
Increase supports for postsecondary education options (college)				
Add sponsored residential to DD Waiver	2	6	3	11
Abolish waitlist	3	2	2	7
Make services available for children	1		1	2
More attendant hours, more flexible hours				
EDCD Waiver process way to cumbersome – need to expand number of fiscal agents		2		2
Need better lists of providers on line			1	1
Need better transportation services, array of providers quality			1	1
Have a tiered Waiver system based on level of need/support	4		2	6
Increase incentives to get more providers to do behavioral support and environmental modifications (too much paperwork, low reimbursement)		2	1	3
Decrease regulations to providers can serve all ages and align guidelines with best practices	1	1	2	4
Add dental services for adults	3	2	1	6
Increase provider pool for those with behavioral needs and complex medical issues	1	1	1	3
Need better assessment of quality of providers that is available to people and families	1	1	3	5
Increase supports and services around transition from high school	3	2	2	7
Better coordination between DMAS and Licensing		1	2	3

Topic: Costs, Rates & Funding

Costs, Rates & Funding Comments	1 st	2 nd	3 rd	TTL
Maintain Medicaid funding	8	1	3	12
Increase access to funding	2			2
Continue sponsored residential		4	2	6
Maintain viable rate for congregate 4 bed or less, many other services inaccessible if 3 bed or less	1		1	2
Community services manual is useful			1	1
Community on track with deinstitutionalization	1	1	3	5
Need flexible Waivers	5	1	3	9
Have rates for extraordinary needs	2	1	1	4
ID Waiver supports not matching needs (those with low needs not using all services available and those with complex needs not getting served)		1	1	2
Improve care giver payment system (give benefits, provider hours cut)	20	10	2	32
Impact of ACA on small providers who have to provide health care to workers		5	1	6
Direct support workers need high pay for stable career	1	5	4	10
State licensure of consumer-directed services		2	4	6
Funding access, eligibility threshold set too high		2	2	4
Home modification funding too low, not easy to access, takes 4 years to access \$20,000		5	4	9
SIS does not capture needs in specific circumstances (low needs at home if parent doing a lot unpaid)			1	1
Increase reimbursement for providers		4	8	12

Appendix E: Additional Comments Received Outside the Forums

Additional comments received after the public meetings/stakeholder forums:

- 1) Thank you for the opportunity to comment. Some of the opinions relate directly to the waivers, while others are being stated in hopes that our state government listens and makes progress. It is obvious that we need to address those in institutions and give every single one of those individuals' high quality community living and care. That is a given. But, I want to speak for the future adults. Those individuals with disabilities who are now in school. While crafting our future, we need to remember that the people being served are changing – slowly, but surely. They are not going to institutions; they are going to school. And, some of these students are fully or partially included in their schools' general classrooms. This number will rise every year – that is a fact. That means more and more young adults with disabilities will be graduating between the age of 18 – 22 with much better educations and skill sets. They will have higher expectations because they have been raised with higher expectations. They will break stereotypical mold in everything that they do. Most young adults with disabilities who are included in school want the same goals that their typically developing peers do. Some of these young adults will go to college – with a regular college experience or one that is tailored for people with special needs. I know only of two programs in VA – GMU and VCU. Sadly, place like ODU had to drop their program due to funding. That is short sighted. Community colleges are also a great option for many students. We need to invest and nurture these programs. They are graduating young adults who are far more independent than any one dreamed. This is a very good thing. Most of these adults want to live as independently as possible. They want their own apartments or houses. They want to be future homeowners. Many have families who want to help – can form some microboards – but still need some logistical and financial help. We need out of the box housing options beyond the traditional group home. We need to do what Lynn Segal from Hope House speaks of – forming strong alliance with AARP and Wounded Warriors who have many issues that overlap with the disability community. It is my vision of the ideal future to see affordable housing that can be purchased or rented by people with disabilities, veterans, senior citizens. All helping each other. Meaningful work gives purpose to any individual. Most people with disabilities can work – in the community. Job coaching and supported employment services funding needs to be raised each year. Job coaching and supported employment should be available to every individual with a disability. Right now, the middle class is cut out, starting in middle and high school, unless families are savvy and change tax forms. Let's stop this practice and make a goal of employing every individual with a disability in the community. Let's start job coaching as early as possible in school. The payoffs for our tax and entitlement structure would be immense. For those individuals who cannot work in the community, Virginia needs high quality day programs. Currently, we have a wide range of quality in a state that should not have anything but the best. What is missing? Love. That's right...love. People with disabilities should have the right to

love, be in relationships, and get married. Love should not be forbidden or penalized. Everyone needs love in their life. In the 13 years I have been advocating for people with disabilities, this is something I have heard loud and clear from individuals themselves. My daughter is 13. She has Down Syndrome. She has been fully included in Hampton City schools since she was 2. She is in 6th grade. She works incredibly hard to earn grades ranging from A – C taking the same classes and tests that any 6th grader does. She loves school and talks about college, but is not sure if she wants to go one day. She wants to have a good job, possibly in graphic design, and her own apartment or house when she grows up. She won't discuss boys yet, but as her mother, I can tell you I want her to be married to a wonderful young man someday. It is the same wish I have for her older sister who is 25. Please think of middle class families who are raising many children with disabilities. Please think of the better education any students are receiving now. Most of all, please collaborate with other organizations and communities to think out of the box. With limited funding and a large need, it will take creative thinking to offer services for everyone.

- 2) We are parents of a child with a disability who has the DD Waiver. We want our voices to be heard about what services should be added to the DD Waiver: community living option (add ICF/ID home); adult day support; and a local respite center (Stafford area).
- 3) I strongly believe that the DD and ID Waivers should be merged and given sufficient funding to serve all those in need. Many children and young adults have both developmental and intellectual disabilities. It is grossly unfair to those with autism that they have no access to community-based housing as they age out of the school system. Similarly, those who were initially labeled with ASD and subsequently found to have ID as well must go to the end of a 10 year waiting list for the ID Waiver. This situation is unfair to the disabled person and their families. Merging the two waivers would eliminate the disparity in available services. Proper funding could then be provided to serve eligible families within a reasonable period by opening up additional slots in the program. It is well known that VA ranks 47th out of 50 states in provision of services for the disabled. This is an outrage for a state with the resources VA possesses.
- 4) I applaud Virginia for undertaking a study of 3 of Virginia's Waivers. For too long, a small number of people have received a lot and a large number of people have received little to nothing. While I am a fan of the increased emphasis on person-centered planning, we have built a system that many parents are led to believe is supposed to completely fund everything their child's wants and needs. My daughter who has significant disabilities has never received services. I think waiting lists are ridiculous. Waiting for what? A list of services that are not flexible? Are underfunded? Are segregated? Although she did get some money from the Individual and Family Support Fund, we wanted to pay the parent to parent program that

helped us more than any professional ever has in 16, but they couldn't take that money. Why do we have family organizations not funded by state agencies? They are doing the lion share of the work helping families navigate our ridiculously complex, siloed system. We have a generation of young adults coming out of inclusive schools who have benefited from being educated with diverse peers - they don't want segregated housing or work settings - they want the same life you and I have. They and their families need comprehensive futures planning support from parent organizations funded by state money. For all of this to happen, you will need to make some very difficult and unpopular decisions, particularly stripping the CSBs of so much power, so that we have an equitable system of supporting every person with a developmental disability with something (maybe not everything they need). We should be looking at innovative postsecondary education programs, self-employment, and living arrangements that work in other states. We need to stop incentivizing segregated work and living situations. We should expect that if the SIS is the tool used to determine need and individual budgets, that people implementing the tool have extensive training and oversight and that they do not work for the same agency that provides services. What a conflict of interest that is. I think you should implement an Amazon type of rating system so people and families receiving service can rate the providers and only buy from those with the highest ratings. Providers need to quit complaining about rates, about paying benefits and vacation time, etc. Parents and siblings are supporting their loved ones with disabilities for 20 to as much as 70 years with no pay, no paid health insurance, little vacation away from the person, and absolutely no training. We do it without complaint because we love our family member and because the system isn't there to do it all for us.

- 5) Thank you for any consideration my ideas many receive. I want to urge the department to identify and incorporate significant system wide common sense administration reforms to reduce the administrative burden on the system and convert savings to directly support persons served. These reforms can come in the way of regulatory reform, paperwork reduction, innovation, technological advancements, etc. Our direct support staff have been required to spend increasingly more and more time and effort meeting administrative requirements at the expense of our primary mission which is to directly support individuals with the most significant disabilities. Increase the Medicaid reimbursement rates to the community-based organizations that provide direct spot services for all individuals with significant disabilities supported by Medicaid so that they are reimbursed at a level that allows them to provide the high quality level of care that these individuals need and deserve. At present, many providers are not able to serve individuals transitioning from Training Centers because they cannot afford to provide the level of care they require. Ensure that regulations for individual and group supported employment are completely aligned with those of the DARS. In recent years, great strides have been made along these lines, but there are still significant

inconsistencies between the DMAS regulations and DARS regulations making it difficult/impossible for providers of employment services to provide supported employment under the waivers. The unit of service should be ¼ hour. Changes to ISARs need to happen quicker and more efficiently so that employment positions are not lost. Approvals for ISE in the waiver need to not require specific schedule of supports as the services based on employment specialist time, not consumer program time. Employment specialists need to be able to bill for travel time to/from employment sites when consumer is not with them.

- 6) The current system in Virginia has many strong tried and true methodologies such as the team approach to services and the person-centered planning that would work in any new system. In the recent transition from Training Centers to community-based services, we found that for the most part, the transition strategies are successful, though the coordination at times was challenging due to different approaches needed in the community vs the institution. As to proposed development of needs based system, that is inarguably logical and its implementation could be very effective. The caveat is that is assessments were not conducted accurately and ethically, the safety of many would be at risk. The problem of insufficient resources to meet each person's needs exists now, and if assessments leading to the creation of individualized budgets were inaccurate, that would put the person in harm's way. Regarding waiver residential services, we have the benefit of extensive experience in supporting adults who came from parental homes, other providers and Training Centers. We have been successful in enabling quality of life in the community, but the most critical issue is the inadequate rate of reimbursement. The \$17.36/hour for congregate residential services is NOVA is grossly inadequate. The supports we deliver to people with staff ratios of 2 staff to 4 people during the day and 1 staff to 4 people at night actually costs 35% more than the current rate. The money is not following the person and has created a barrier for all wishing to receive community services and especially those with the most extensive medical or behavioral needs. And, increased the safety risks for individuals currently in the system. A negation of person-centered services when plans are created with legitimate important outcomes cannot be properly implemented due to the lack of resources. What drives the cost of residential supports in NOVA? Providing essential services even when we cannot get reimbursed (general supervision, support when people are hospitalized); providing extensive training plus one-to-one coaching to every direct support staff; maintaining cumbersome daily documentation of the services and responding to audits and reviews; maintaining required liability, crime, D&O, and workers comp insurance with increasing premiums; providing health insurance and other benefits for all full time staff; offering paid vacation time so staff can periodically rest from a demanding and important job; and meeting all the regulatory standards and reporting to CSBs, human rights, licensing to provide reports, conduct investigations, and attend meetings. A second problem for providers is the delay of funding for months after services are started. When providers

expand and start providing the services that are initially done without payment and it often goes on for several months. Licensure requires liquidity of 90 days of operating budget as reserves but those reserves disappear rapidly under this delay of payment situation. Most providers cannot afford to front thousands for months for each person coming into our program. Other problems are the unavailability of startup funds, environmental modifications for private provider homes, current unreliable Medicaid transportation system, management of assistive technology funds, and the existence of survivor benefits that unintentionally place individuals into suddenly no longer qualifying for Medicaid.

- 7) Thank you for the opportunity to comment on the redesign of the Intellectual Disability (ID), Developmental Disability (DD) and Day Support (DS) Waiver programs. As a statewide organization for Virginians with intellectual and developmental disabilities (ID/DD) and their families, The Arc of Virginia has a vested interest in the Waiver Reform process. We strongly believe input of those who actually receive ID/DD services, as well as those who are on waiting lists for services, is critical to both the redesign process and the ultimate success of the new ID/DD waiver program. The Arc of Virginia is composed of 25 local chapters across the Commonwealth whose members include people with ID/DD, family members, professionals and concerned citizens. The Arc of Virginia convened a "Committee on the Future" to help develop our recommendations about how to improve access to ID/DD waiver services and quality of services provided to waiver participants. This Committee included local chapter leaders, national experts, self-advocate organizations, private providers and representatives of other family organizations such local Down Syndrome Associations and the Autism Society. The recommendations are submitted on behalf of The Arc so that they may be incorporated in the ID/DD Waiver reform effort.
- 1). There should be one, robust and comprehensive "DD" waiver program to serve all Virginians with ID/DD. The program should emphasize inclusion, integration and family support across the lifespan and must also offer all participants access to high quality supports consistent with their individual needs. Payment rates and the individual planning process should promote competitive employment, integrated housing, meaningful relationships and community inclusion.
 - 2). The new ID/DD Waiver program should afford participants the freedom and authority to decide how waiver dollars are allocated on their behalf, using individual budgets that are based on the results of a comprehensive assessment of the individual's support needs and personal aspirations.
 - 3). The Commonwealth's level of care (LOC) determination process for ICF/IDD services should be revamped so that the functional needs of potential recipients of HCBS waiver services are fairly assessed. The "level of functioning" survey currently in use does not give a complete, accurate picture of an individual's need for services.
 - 4). DMAS officials, in collaboration with DBHDS, should explore the feasibility of establishing a Section 1915(i) state plan coverage for individuals with mild to moderate intellectual and developmental disabilities, who may not meet the ICF/IDD level of

care criteria but may require some level of support to avoid homelessness or institutionalization in the future. 5). Budget transparency should be emphasized in the administration of the ID/DD waiver program and cost savings should be reinvested to improve access to, and the quality of, community-based services and supports. 6). A holistic approach to administering the ID/DD waiver program should be adopted, beginning with improving access to services and streamlining the process of obtaining those services. The intake process also should include a full review of other funding mechanisms that are currently supporting people with ID/DD, including the EDCD Waiver, HIPP, VR programs, the Comprehensive Services Act and the EPSDT program. For the area of Access and Planning, people with ID/DD and their families report that Virginia's service system is difficult to navigate and often they face significant challenges finding the services that they need. Families are left with the burden of navigating multiple agencies, often without the assistance of a case manager or "community guide." Families also report that once they do locate services, local agencies often provide inconsistent or inaccurate information. Thousands of people with ID/DD also face long waiting lists for community-based ID/DD Waiver services. As of September 2013, more than 6,500 people were on the Intellectual Disability Waiver waiting list and an additional 1,300 were on the Developmental Disability Waiver waiting list. More than half of these individuals are in urgent need. Examples of urgent need criteria include living with an aging caregiver, living with an ill caregiver, risk of homelessness and risk of abuse or neglect. There are other people with ID/DD who are unable to access ID/DD Waiver services due to Virginia's strict eligibility criteria for level of functioning. These individuals just need minimal supports in order to avoid institutionalization. Without these support though, individuals with ID/DD often intersect with the criminal justice system, homeless shelters or mental health facilities. At one time, state funding outside the Waiver system was provided to support these individuals, but that funding has since eroded due to CSB budget cuts. We offer these recommendations to improve Access and Planning: Streamline and standardize the process of applying for and accessing supports and services. This should include a single point of entry (SPE) for ALL people with developmental disabilities. The SPE agency should be responsible for intake, eligibility determination and the provision of consistent and reliable information. Provide case management to all people with ID/DD who are in need. Currently, individuals who need less tend to fall through the cracks. Individuals who are on waiting lists often receive little assistance in locating other sources of generic and specialized support. The case management system must ensure that people with ID/DD are properly linked to services, regardless of the HCBS waiver status or eligibility. The intake process also should include a full review of other funding mechanisms that are currently supporting people with ID/DD. Ensure that case managers are equipped to serve all people with ID/DD and their families by providing adequate training on ID/DD services and supports. This training should not be limited to services funded through the ID/DD waiver programs; it should address other services available to people with ID/DD (i.e.,

the Individual and Family Support program, EDCD Waiver, VR programs, HIPP, mental health supports, the Comprehensive Services Act and the EPSDT program). The role of case manager must be examined. Families need help navigating and accessing community-based supports. Currently, case management services are heavily focused on gate-keeping and paperwork functions. What steps need to be taken to improve the capacity of case managers to assist individuals and families in accessing and selecting the proper supports given their unique needs? Case managers should be funded to allow better coordination of services. Case managers should act as liaison between various agencies that are involved with individuals on their caseload (DSS Medicaid Eligibility, DARS, SSI, etc). Systems navigation should be accomplished by presenting the services of various agencies to the person, instead of referring the person from one agency to another. To prevent institutionalization, the Commonwealth should fully fund the urgent need waiting list for the ID and DD waiver programs. This funding should be allocated on a “triage” basis, with waiver slots allocated based on urgency of need. When urgent needs are fully met, waiver slots should be allocated on a first-come, first served basis to those on “non-urgent” waiting lists. Explore the feasibility of establishing a Section 1915(i) state plan coverage that serves people who have ID/DD but do not require an institutional level of care. Institutional admissions, homelessness, abuse and neglect can be avoided in the future of people with mild ID/DD if they receive early access to essential supports. These supports cannot be furnished through the ID and DD waiver programs unless and until an individual meets the ICF/IDD level of care criteria, but a Section 1915(i) may offer a way of affording such individuals access to supports—before their needs escalate and become very costly. Move to an outcomes focus with creative planning for supports. Make sure “person-centered planning” is real, not just tidy paperwork. Put together a spectrum of supports that work together, moving away from “paid staff only.” Support families from the beginning. Consideration should be given to establishing a statewide registry of individuals with ID/DD that begins with pediatricians and/or early intervention system and provides lifespan tracking. This could help ensure seamless transitions (early intervention, school transition, locations, etc.) over time. The Commonwealth’s level of care (LOC) determination process for ICF/IDD services should be revamped so that the functional needs of potential recipients of HCBS waiver services are fairly assessed. The “Level of Functioning” survey currently in use does not give a complete, accurate picture of an individual's need for services. There are also concerns that the eligibility criteria may be applied inconsistently depending on the evaluator’s training, experience and familiarity with the individual being assessed. If the Supports Intensity Scale (SIS) is used as part of the eligibility determination process, scale assessments should be conducted by independent evaluators who are highly trained to ensure inter-rater reliability. If information gathered through the SIS is used in establishing individual budgets, it should be used in combination with other information that takes into account as individual’s dreams, aspirations and family circumstances (e.g., single parent, family illness). For System

Management, while DBHDS has been designated as the lead program agency for ID/DD services, it does not have budget authority necessary to fulfill this role. There is not an ID/DD “program budget.” Instead, DBHDS oversees the Training Center budget and DMAS continues to have authority over the ID/DD Waiver budgets and private ICFs. There is little budget transparency in these programs, especially when it comes to cost savings achieved by downsizing state institutions or moving away from segregated services. Significant “culture change” is needed in the Virginia ID/DD system. While a number of specific activities are underway to fulfill the terms of the DOJ agreement, there has been little emphasis on the “paradigm shift” needed to inculcate person-centered practices into the day-to-day delivery of ID/DD services. Who is working on this at the local/CSB level? How are case managers getting the message? Who is striving to change the culture at the provider level? Recommendations for System Management include: While there are many stakeholders in the ID/DD system, there should be more interest and dedication to working with individuals with ID/DD and their families as they are the most affected by the quantity and quality of services. Individuals and families should be considered the primary stakeholders in the ID/DD system. Initiate culture change initiatives at the state, CSB and provider levels. This culture change should be aimed at promoting community integration, independent living, supported employment, family support, self-determination and supported decision-making. Improve the transparency of the policymaking process and continually seek stakeholder input. Data collection and reporting should be proactive rather than reactive. All state agency meeting minutes (including subcommittees/workgroups), program budgets and data reports should be posted in a timely manner on the DBHDS website. Transfer ID/DD waiver and ICF/ID budget authority to DBHDS, which currently serves as the lead program agency for ID/DD waiver programs. Consolidating budget authority and day-to-day program management in a single agency will allow DBHDS to effectively manage resources to better serve the population. DBHDS should develop mechanisms to gather and report cost savings achieved through the provision of ID and DD waiver services and ensure that such cost savings are reprogrammed to finance supports for wait-listed people and families. The Virginia General Assembly in turn should reprogram savings achieved through the closure and eventual sale or lease of Training Center property to assist individuals who are wait-listed for ID/DD services and support. Under the area of Financing of Services and Supports, while Waiver Reform is anticipated to take effect in FY 2016, Virginia has not implemented essential interim strategies to help people with complex needs live in the most integrated settings. This has resulted in a resurgence of the ICF/ID model and a continued focus on large, congregate settings. This is at odds with Virginia’s stated commitment to promote cost-effective, high-quality, integrated community services for people with ID/DD, regardless of the complexity of their support needs. Current waiver utilization rates and the program’s structure incentivize large, segregated settings and create barriers to community integration. There is high utilization of group homes in Virginia and 37% of the individuals

residing in group homes are living in facilities that house seven or more residents per home. Very few waiver participants (less than 5%) live in their own home with supports furnished through either the ID or DD Waiver program. In the same vein, very few people are receiving individual supported employment (2.8%) through either the ID or the DD Waiver program. There continues to be a high utilization rate of center-based daytime activity programs and sheltered workshops. Individuals with ID/DD also report difficulty accessing consumer-directed services, a support that promotes integration and helps people live in their own home or the home of a family member. Examples of barriers to consumer-directed services include difficulty obtaining authorizations, delayed payment to direct support professionals, lack of support worker benefits and inadequate reimbursement rates. For Financing Recommendations, Virginia must ensure compliance with the Americans with Disabilities Act, as the Act has been interpreted by the U.S. Supreme Court in its Olmstead ruling, while preparing for implementation of the new ID/DD Waiver program. Since changes to the ID/DD Waivers are not anticipated until FY16, Virginia must provide adequate bridge funding to help facilitate successful transitions from Training Centers to the community and prevent the unnecessary institutionalization of people currently living in the community. The new ID/DD Waiver payment rates and delivery structure should emphasize and promote competitive employment, integrated housing, meaningful relationships and genuine community inclusion. This will help the new Waiver program comply with many provisions of the DOJ Settlement Agreement. The new ID/DD Waiver rates should reflect the true cost of providing services. The reimbursement structure of the revamped ID/DD waiver program should take into account the support needs of each individual and should also reflect regional economic differences. Direct support professionals should receive fair and timely compensation. The new ID/DD Waiver program should promote self-determination using individual budgets. It must give people with ID/DD freedom and authority to decide how Medicaid waiver dollars should be allocated on their behalf, utilizing individual budgets that are developed based on an assessment of personal needs and aspirations. Local dollars should be leveraged to improve access to HCBS services. To the maximum extent possible, local CSB revenues used to support ID/DD services should be matched with federal Medicaid dollars and the local dollars that are freed up should be used to expand and strengthen HCBS services for persons with ID/DD within the affected local jurisdiction. Restructure reimbursement so that individuals with intellectual and developmental disabilities can receive ID/DD waiver supports while they are in the hospital. Don't penalize providers for helping people with ID/DD maximize natural supports (i.e. lack of reimbursement while away from home). Re-examine the role of the Elderly and Disabled with Consumer Direction (EDCD) waiver program and determine how its current use by people with ID/DD relates to the waiver reform process. The EDCD waiver program essentially functions as a "supports waiver" for over 1,000 people with ID/DD who are on ID/DD waiting lists. But the EDCD waiver program operates under an entirely separate set of state rules and through a

separate provider network. ID/DD participants in the EDCD waiver program do not have access to the same scope and intensity of support that they otherwise would receive under the existing DD and ID waiver programs. Also, the instrument used to determine EDCD Waiver eligibility (the Uniform Assessment Instrument) does not adequately assess the service and support needs of individuals with ID/DD, especially children with disabilities. Pursue a process for conversion from the ICF model. Once the Waiver Reform process is complete, begin with a moratorium on approvals for new ICFs. Include in the waiver a transitional provision that facilitates an individual's movement from ICF to waiver services. Examine the role of the Comprehensive Services Act, especially as it relates to children with ID/DD who are at risk of placement in a segregated setting. Include in the waiver a transitional provision that facilitates movement from foster care, nursing home or large, private residential facilities. Related to the area of Service Delivery, as mentioned in the "Financing" section above, Virginia relies more extensively on large, congregate settings to service persons with ID/DD than most other states. In addition, the state has low utilization rates in the most integrated service settings and little focus on services that help promote inclusion and lifespan family support. People with ID/DD moreover continue to be denied access to essential services, such as adult dental care and private duty nursing services. Quality improvement of all ID/DD services continues to be a concern. There is a low threshold for becoming a new, licensed provider of ID/DD services and a high threshold for being placed on provisional status. Despite many recurring reports of sub-standard practices within the ID/DD system, very few providers are placed in "provisional" status. Action also must be taken to improve safety and quality in the transportation system. There have been many reported cases of abuse and neglect when individuals are using Medicaid-funded transportation. Despite several attempts to rectify problems with Logisticare, the state's Medicaid transportation broker, serious quality assurance issues abound. Many Logisticare providers show up late or don't show up at all, which has far-reaching effects on the lives of people with intellectual and developmental disabilities and often their families. Many Virginians with intellectual and developmental disabilities and their family members still have difficulty obtaining community-based crisis stabilization services and support to prevent crises. While the START program has been an important step forward, there is a lack of coordination with CSB emergency service personnel and, as a result, there continues to be unnecessary hospitalizations and involvement with law enforcement. Finally, there is a heavy emphasis on guardianship in Virginia's ID/DD system and little education about supported decision-making. In addition, when an individual with ID/DD receives a Waiver slot, an "Authorized Representative" is appointed. This "Authorized Representative" (AR) essentially serves as a Guardian of the person in many areas of state law, even though there is no formal process of appointment or requirement that the AR file regular reports. Service Delivery

Recommendations: Make changes to the quality improvement and licensure processes to ensure that the "bottom" providers are identified, their shortcomings remediated, and the

provider is decertified if remediation efforts fail. Lower the threshold for “provisional” licensure status and make it easier for DBHDS to revoke licenses if there is evidence of systemic non-compliance that has resulted in harm to service recipients. If multiple, similar problems occur in a program, DBHDS should have the capacity to examine root causes and institute solutions system-wide. The Waiver Reform study should review Virginia’s model of providing transportation to people with intellectual and developmental disabilities. The role of Logisticare, as broker of transportation services, should be closely examined. If Logisticare is retained as the state’s transportation broker, safety and quality improvement systems must be put into place and there must be an accountability mechanism at both Logisticare and DMAS levels. Create a consumer-directed option for all direct services provided through the ID/DD Waiver program. Ensure that the reimbursement rate is reflective of true cost of providing each service and takes into account the support needs of the individual. Improve access to assistive technology, environmental modifications and nursing services. The current process of accessing these supports is burdensome and needs to be simplified. Waiver-funded services should help people enjoy natural supports (such as family and friends) without sacrificing the professional supports that enable a full, meaningful life in the community. The new ID/DD waiver program should focus on lifespan family support, which includes going beyond respite services. The new ID/DD waiver program should be designed to help people with intellectual and developmental disabilities to age in place. This means allowing flexibility in supports for people with ID/DD to “retire” with ready access to any specialized medical services they may need. Modify waiver service descriptions to promote more creativity, innovation and integration. For example, the revised waiver program should seek to promote the development of microenterprises as an option for supported employment. “Integrated day” services also might be permitted to promote individualized services and true relationship building in the community. Supported living should include flexibility in billing for financial management, overnight monitoring (including use of technology) and health care management. Streamline the process for accessing supported employment so that people aren’t discouraged from seeking jobs in integrated settings. The structure of the current system can sometimes make the process daunting and cumbersome. Revisit the process of appointing an “Authorized Representative” and the role of the AR within the service system. Can the role be modified to promote supported decision-making instead of having the AR act as a guardian with plenipotentiary powers? How can a “presumption of competence” be built into the determination of competence of people with ID/DD? Include “peer mentoring” and “community guide” as covered services in the revamped ID/DD waiver program. These services should be designed to help individuals and families gain access to systems navigation and assistance accessing supports, while ensuring system-wide transparency. Include “adult dental” as a Medicaid-funded service. Preventive care may eliminate many “behavioral challenges” and more costly interventions. Include private duty nursing as a ID/DD Waiver service. Many families report

that they lose this service when the individual transitions from the EPSDT program at the age of 21. While the ID/DD Waiver includes skilled nursing, it does not include private duty nursing services.

- 8) I am writing on behalf of the Virginia Board for People with Disabilities (the Board) to provide written comment on redesign of the three Medicaid Waivers managed by the Department of Behavioral Health and Developmental Services (DBHDS): the Intellectual Disability (ID) Waiver; the Individual and Family Developmental Disabilities (DD) Waiver and the Day Support Waiver. Two Board staff attended the Comment Forum in Colonial Heights and were impressed by both the level of attendance and the amount of feedback gathered in a short period. We also had the opportunity to participate in an interview with HSRI representatives. The Board has had a long interest in Waiver reform, and wishes to take this opportunity to make additional comments. The Board has made recommendations to improve the Waivers and related services in each of the three editions (2006, 2008, & 2011) of our comprehensive report, Assessment of the Disability Services System in Virginia. In each edition, a consistent recommendation has been that Virginia develop a comprehensive, “universal” waiver based on functional criteria rather than diagnosis. The DBHDS effort to revise the three waivers is a critical step towards that goal. In the long run, a universal waiver can be easier for the public to understand and use as well as more efficient to administer, operate and monitor. The Board’s comments are organized by the heading used at the Comment Forums held by HSRI, which are preceded by key concepts and principles for the redesign. The newly designed Waiver must support the vision of community inclusion, citizenship, opportunity, and full participation aspired to in the Department of Justice Settlement Agreement. Features and content of the new waiver should be flexible and result in: promotion of self-direction, individual autonomy, choice and consumer control; effective use of all available resources, including natural and community supports; and creation of a unique, individualized service package that meets his or her needs across the lifespan. The new waiver should better enable Individuals with ID/DD to live the life that they want to live, not one based on what a provider can accommodate. Please refer to the policy principles espoused by the Board in its Benchmarks for Evaluating Public Policy in Virginia <http://www.vaboard.org/downloads/VBPDBenchmarksPagebyPage.pdf>. The Board strongly supports creation of a single robust, comprehensive “DD Waiver” from the current three waivers (ID, DD and Day Support) to serve all Virginians with ID/DD, regardless of the complexity, or evolution over time, of their support needs. All services currently in these waivers should be available to those who choose and need that service, including group sponsored residential, small group home (after being given information another support options), and family caregiver training. Although the Elderly and Disabled with Consumer Direction (EDCD) Waiver is not part of the redesign, consideration must be given of the numerous individuals with ID/DD who now receive services under that that Waiver and may or

may not be on the ID and DD Waiver wait lists. Many individuals who are on the DD or ID Waiver wait lists may be eligible to receive services from the EDCD waiver, but are unaware of their eligibility. In effect, the EDCD Waiver functions as a support waiver and cannot be ignored as consolidation and redesign are undertaken. As stated in previous Board Assessments, accountability for service quality and effectiveness is essential not only to better individual outcomes and safety but also to ensure prudent use of taxpayer funds. Individuals with ID/DD and their families need reliable, knowledgeable, skilled assistance in navigating the service system across the lifespan. Improved methods for individuals to have complaints or problems addressed are indicated and would assist DBHDS in identifying and resolving problem areas. DBHDS quality assurance/improvement processes and oversight of case management (and when/if applicable, service facilitation) will be needed on an ongoing basis. The Board additionally recommends that the new waiver design process continue to be transparent: a draft of the new waiver should be made available for public comment prior to application submission to CMS. Communication to stakeholders regarding the rationale for changes as well as implementation plans will be needed. It is also important that fiscal studies of the impact from Waiver redesign should address cost avoidance such as nursing home or ICF/ID diversion. Having both the ID and DD Waiver currently results in a bifurcated definition of developmental disability. The new Waiver should eliminate this bifurcation by eliminating the requirement to obtain, or rule out, the diagnosis of intellectual disability. An intellectual disability is a developmental disability (one of many), and having a diagnosis of DD should be adequate to determine eligibility. Criteria should be based on functional level of impairments, not diagnosis beyond that of developmental disability. Eligibility assessment tools. The Universal Assessment Instrument (UAI, used for the EDCD Waiver), the Level of Functioning (LOF, used for the DD and ID waivers) and the Supports Intensity Scale (SIS, used with individuals who have intellectual disabilities) as well as the current processes for eligibility pre-screening should be carefully examined not only for reliability and validity, but also for appropriateness for and consistency with principles of person-centered services. The current organizational conflict of interest with respect to screening, assessment, eligibility, and service delivery must be eliminated. Eligibility determination should not be made by the same entity that provides case management; case managers and service providers should not be involved in decisions on who obtains a waiver slot or be able to refer to their providers' own services. Once determined eligible for the new DD waiver, individuals should be fully informed of provider choice options, including choice in case management as is currently provided for in the DD Waiver. Waiver Wait Lists: Ideally, Virginia would fund Medicaid so that all those now on the ID or DD wait list would be awarded a slot or otherwise receive services. That level of funding is not likely at the present time. Waiting list processes and criteria therefore need to be reconsidered, to include review of methods used in other states, to determine the best way to ensure that those individuals with the greatest need are served first on a statewide basis. Having thousands of people on an

“Urgent” Waiver wait list for long periods of time weakens the credibility of the current method. Development of a clearer hierarchy of needs as well as emergency criteria is indicated. After a review of past allocations, a percentage of the Waiver slots each year should be set aside for emergency cases as well as for individuals in the hospital or other acute care settings as part of nursing home/institutional diversion. Individualized Budgets. Medicaid HCBS policy recognizes two basic types of self-direction: employer authority and budget authority. Participants exercising employment authority are authorized to hire, fire, and supervise personal support workers. The more comprehensive form of self-direction, referred to by CMS as budget authority, allows participants to purchase goods and services as well as supervise personal support workers and manage expenditures within the limits of a specified budget allocation. Currently VA Waivers offer consumer direction which, as designed and managed, falls in the employment authority definition. The National Council on Disability, in its report *The Case for Medicaid Self-Direction: A White Paper on Research, Practice and Policy Opportunities*, <http://www.ncd.gov/publications/2013/05222013A/> describes the budget authority model (often referred to as individualized budgets) as one where participants are allowed to use their funding allotment to not only hire personal support workers, but also to purchase other goods or services designed to meet disability-related needs. Some of these goods and services may substitute for human assistance or otherwise enhance the individual’s independence (e.g., assistive technology, home modifications, transportation services, laundry services, meal services, and personal care supplies). Participant-directed goods and services usually include items that would not be covered under traditional home and-community-based (HCBS) programs and that may be purchased from non-traditional sources. The Waiver design study should include an in-depth and comprehensive review of state models of implementation and outcomes of individualized budgets. Virginia’s new DD Waiver should be one that addresses today’s needs but also the needs of a service system that is building increased capacity and competency in the years to come. The new Waiver should reflect opportunities for increased individual control of service dollars and budgets. Prior to implementation, pilot projects of the most promising models for Virginia should be funded to avoid known and identify unexpected problems or misuse of resources. Individualized budgets in the Waiver should not be funded to serve in effect as a supports waiver with low fixed caps on service plan authorization amounts that don’t meet the service and support needs of recipients. Case Management: As mentioned previously, the new system should require choice in case management, not only within providers but between providers (public and private). The National Council on Disability (NCD) endorses these core characteristics of conflict-free case management (which were identified in the Balanced Incentive Program guidelines and regulations for long term care by the Centers for Medicare and Medicaid Services): “Responsibility for providing case management services is separate from responsibility for providing direct services and supports. Case managers are not employed by the entity providing

services. Case managers are not responsible for determining individual funding levels. Persons performing evaluations and assessments or developing individual plans of care cannot be related by blood or marriage to the individual or any of the individual's paid caregivers." The role of case managers should be to effectively coordinate service provision in collaboration with the individual and their family. Doing so requires up-to-date knowledge of state, regional and local resources that can support the individual, and a true understanding and commitment to the culture of person centeredness, community integration, and community inclusion. Service facilitation, while important under the EDCD waiver because there is no case management support, should be optional for the new comprehensive waiver as it now is for the ID waiver. Service facilitation can be provided by the case managers under the new waiver; and in cases in which services are stable, service facilitation can be redundant and constitute wasteful Medicaid spending as well as unnecessary intrusion for service recipients. Whether optional or required, if service facilitation is maintained under the new waiver, there must be increased efforts on training and quality improvement of the service facilitation service. Currently, numerous anecdotal reports indicate that the quality of service facilitation is extremely uneven and variable.

Dental Coverage/Services. The new Waiver should cover routine preventative dental services for adults. This can result in reduced Medicaid expenditures over time through: avoiding more invasive, expensive procedures that might have been prevented through routine dental care and avoiding emergency room use for dental problems. The state Joint Commission on Health Care this year conducted a study on policy options for doing so under the Medicaid State Plan, and will be making recommendations for legislative action later this fall.

Live-In Caregiver. As mentioned under Key Concepts, the new Waiver needs to be flexible enough to allow for a variety of living and support options. One enhancement to Virginia's new Waiver, which would allow for such flexibility, is the inclusion of the Live-In Caregiver provision in the Waiver design and application (See section 441.310, 2.ii, Code of Federal Regulations):

- 2) The cost of room and board except when provided as—(i) Part of respite care services in a facility approved by the State that is not a private residence; or (ii) For waivers that allow personal caregivers as providers of approved waiver services, a portion of the rent and food that may be reasonably attributed to the unrelated caregiver who resides in the same household with the waiver beneficiary. FFP for a live-in caregiver is not available if the beneficiary lives in the caregiver's home or in a residence that is owned or leased by the provider of Medicaid services (the caregiver). For purposes of this provision, "board" means 3 meals a day or any other full nutritional regimen and does not include meals provided as part of a program of adult day health services as long as the meals provided do not constitute a "full" nutritional regimen. The Live-in Caregiver provision allows Medicaid reimbursement for a portion of the costs of room and board for a live-in care giver in an individual's own home. Including the Live-In Caregiver provision in the redesigned Waiver provides increased flexibility to accommodate individual choices and circumstances and promotes community integration.

Environmental

Modifications. The new DD Waiver should allow an individual's environmental modification dollars to be used to improve accessibility and other needed modifications in their chosen living environment, including small group homes. (See funding section below for additional information on this.) Doing so could improve available housing so individuals may "age in place" as needs change and increase the accessibility of current homes. Current Waiver reimbursement rates are arbitrarily set and do not reflect the reasonable, customary reimbursement for the costs of providing services. The current Waiver rate structure does not take into account individual living choices, needs, or natural and community supports. Reimbursement should reflect the costs of providing the Waiver services. Rates should allow for reimbursement for general supervision during overnight hours and during hospitalizations when a provider must have staff at the hospital. They cannot be reimbursed under the current system. Rates should incentivize inclusive —not segregated— options not only for residences but also for competitive work (rather than day support or sheltered workshops). Providers should not be penalized for providing person centered services that promote social and family relationships and employment. Consistent with the goals outlined in the Department of Justice (DOJ) Settlement Agreement, the new Waiver should incentivize in-home supports and separation of housing and services. While this concept may be new to some service providers or some people receiving ID Waiver services, individuals receiving DD Waiver services have been using these services to live in their own apartments or homes for years. This is not a new model and should not be promoted as such. DD Waiver recipients, case managers, and providers can help educate state and local agencies and providers on how this has been successfully done. Medicaid reimbursement rates for complex dental care now covered for adults, such as surgical procedures, remain below the costs for such services: specialized equipment, instruments, or staff with additional training are needed in such instances, and dental practices may experience higher liability insurance rates for providing complex procedures. Medicaid reimbursement rates should be set at levels that cover the costs of any dental services for individuals with disabilities. Additionally, funding should be made available for preventative and routine dental services, which takes into account staff training and extra time needed to deliver the dental care and education appropriately. As reported to the Commonwealth's Joint Commission on Health Care this month, routine dental care can generate cost saving to the Medicaid program by preventing use of Emergency Rooms to address tooth infection or pain resulting from lack of regular teeth cleaning and care. Service Caps. Arbitrary service or financial caps should be avoided. Examination of funding caps for current Waiver services that promote independent living and "aging at home" (such as assistive technology or environmental modifications) should be conducted to ensure appropriate levels exist. An essential part of such examination is a longer view cost/benefit analysis which considers the cost-avoidance of institutional or more labor intensive services. An individual may need \$10,000 in environmental modifications, rather than the current \$5,000 cap, in order to

successfully live in the community and avoid more expensive settings or labor intensive supports. Relatedly, as technology continues to improve, funding for technology (e.g., “smart” homes) that promotes aging in place, independence and inclusion should be available. New waiver design and funding should enable individuals with ID/DD to receive the services/supports that they need, no more and no less, in a timely fashion and be flexible and responsive to functional changes over time that are natural to aging. At the same time, services should only be authorized for as long as they appear to be efficacious. For example, some individuals receive “pre-vocational” services for years. Pre-vocational services are meant to be time limited with the goal of moving an individual into employment. After a reasonable period of time, an individual should be employed if they choose to be or, if they do not desire or are unable to obtain employment, the pre-vocational service should be ended and the individual should receive the supports needed to participate in activities that are meaningful to him or her. Leveraging Available Resources and Opportunities: During implementation of the DOJ Settlement Agreement, the Commonwealth will experience significant growing pains as it develops a more robust community-based system for people with ID/DD. The task ahead will require strong, consistent leadership and ongoing resources. Leveraging all available fiscal opportunities is essential to meeting the Settlement Agreement requirements. Accessing all available resources and federal policy initiatives that could bring resources to Virginia should be a priority. Examples include the feasibility of accessing Community First Choice 1915 (k) Option established under the Affordable Care Act of 2010. The “Community First Choice Option” lets states provide home and community-based attendant services to Medicaid enrollees with disabilities under their state plan. It provides a 6% increase in Federal matching payments to states for expenditures related to this option. Another possibility is the use of a Section 1115 Demonstration Grant. The Social Security Act gives the Secretary of Health and Human Services authority to approve experimental, pilot, or demonstration projects that promote the objectives of the Medicaid and CHIP programs. The purpose of these demonstrations, which give States additional flexibility to design and improve their programs, is to demonstrate and evaluate new policy approaches.

- 9) There should be one comprehensive Waiver to serve all individuals with ID/DD regardless of the complexity of their support needs. This Waiver should emphasize inclusion and integration. The present system is difficult to navigate and families get discouraged, many delay applying. Revise the Waiver eligibility so that individuals with mild/moderate ID/DD can access supports too. These folks are being left behind because there is no funding and unfortunately most of them are under employed, if employed, and have no housing options. Improve the access to services. No one should have to be on a wait list for several years. Services are needed immediately and they won’t go away only get worse without the proper support. Last but not least, rates to providers need to be adequate to serve individuals, especially those with

complex needs and the rates should adjust for inflation, not having to beg every time to the General Assembly for years before getting a small increase approved.

10) On behalf of vaACCSES and the Virginians with disabilities that we serve, thank you for the opportunity to comment on the needed redesign of the Intellectual Disability (ID), the Developmental Disability (DD), and the Day Support (DS) Waiver programs. Established in 1977, vaACCSES is a not-for-profit state-wide association of community-based organizations that provide quality services including employment, day support, residential, in-home, benefits assistance and work incentives, and other vital community-based support services to Virginians with all types of disabilities. Our members include both private providers, not-for-profit providers and our CSB partners that provide day support and employment services. Currently, our 37 member organizations serve over 12,300 Virginians with disabilities on an annual basis. Recommendations: There should be one comprehensive “DD” waiver program to serve all Virginians with ID/DD. Combining the current ID, DD and Day Support Waivers will reduce duplication and inconsistency between the waivers, as well as reduce the myriad of complex systems that families and individuals must navigate. The Wait List for individuals with “Urgent Needs” continues to far exceed the annual slot allocation. The annual allocation of waiver slots needs to be increased to keep pace with and to eventually eliminate the ever increasing Wait List. Waiver services must be broadened to include: General supports and overnight general supervision for residential services; High Intensity support for individuals in group supported employment; Provision of mental health supports that overlap with an individual’s disability related support needs; Dental, vision and hearing services; Transportation - payment for transportation to and from activities outlined in an individual’s approved plan of care; and, The ability of individuals to “pool” Medicaid resources to secure needed supports. One example could include permitting three individuals sharing the same residence to hire one person or firm to do nursing supports. Diminish over-regulation and unfunded mandates on community-based service providers. Significant “common sense” administrative reform needs to be implemented to reduce the administrative burden on service providers of excessive and complex documentation requirements. This can include regulatory reform, “paperwork” reductions and technological advancements to name a few. Providers have increasingly been required to utilize more and more direct service staff time and effort to meet administrative requirements at the expense of our primary mission which is to support and provide quality services to individuals with significant disabilities. Transportation needs to be included as a waiver service. The current Medicaid SPO transportation contract between DMAS and Logisticare does not provide reliable and safe transportation on a consistent basis for individuals with special needs. The lack of transportation reliability creates frequent safety concerns, results in individuals missing important services, and often impacts providers losing reimbursement when the service day is shortened unnecessarily. Consider establishing an

Administrative Law-type process with independent administrative reviewers that would have the authority to direct the state to allow changes, increases in services, etc. Current appeals can simply be denied and “life goes on”. Neither not-for-profits nor individuals and their families have the time or money to engage in a hopeless appeals system that is administered by the same department that originally denies a service, etc. Improve the transparency of the policymaking process and continually seek stakeholder input. Data collection and reporting should be proactive rather than reactive. All state agency meeting minutes (including subcommittees/workgroups), program budgets and data reports should be posted in a timely manner on the DBHDS website. Recommendations to Improve Services and System Financing: Align waiver provider rates with the true cost of delivering individualized, person-centered quality services in accordance with regulatory and accreditation requirements. Waiver rates must address the complex medical and behavioral needs of individuals, support smaller staffing ratios if needed (i.e. 1:1 or 1:2), and support regional economic costs of developing and providing services. This is the only solution to ensure the availability and choice of community-based providers for individuals funded by the waiver. With the exception of the cost-based individual supported employment model, the current “one size fits all” reimbursement methodology has resulted in a significantly underfunded community service system. The “rate gap” between the current “one size fits all” rates and actual costs of care seriously undermines access to community services for families and individuals. Waiver services must be broadened to include behavioral supports and intervention as well as therapeutic supports. Currently, therapeutic consultation is reimbursed but not the behavioral plan implementation recommended by that consultation. The new waiver must be structured to allow billing for nurses to work with individuals on a daily or as needed basis including monitoring. Nursing services need to be simpler to authorize and document. Small time intervals for units of service and corresponding rates should be lengthened to increase flexibility in service delivery and to eliminate tedious paperwork that does not add value to service delivery. Units for day support and group supported employment can be lengthened to a daily, weekly or even monthly rate. The same can be done with residential units of service increasing them from an hourly rate to a weekly or even monthly rate. The new waiver must include a clear annual cost of living indicator to ensure that a waiver service dollar does not erode over time and its purchasing power does not diminish. An annual adjustment based on the CPI is recommended. The rate for Community-Based Day Support must be significantly higher than the rate for Center-based Day Support. A higher rate would incentivize movement to the community and also cover increased costs of transportation, more sophisticated program planning and community development, and higher level staff qualifications. Local dollars should be leveraged to improve access to waiver services. To the maximum extent possible, local government revenues used to support ID/DD services should be matched with federal Medicaid dollars. This would free up local dollars which could be used to expand and strengthen services for individuals with ID/DD

not eligible for waiver services. The new waiver should allow for the provision of start-up funding for new residential services both during transition and during the recruitment and training of staff. A period not less than 30 days is recommended. A new service (similar to adult day care) is needed to support individuals whose service needs have become more intensive and whose tolerance and stamina for “active treatment” has been affected. Individuals should be able to age in place and to have their service plans changed accordingly. Allowing flexibility in supports for individuals with ID/DD will allow them to “retire” with ready access to any specialized medical or therapeutic services they need.

Recommendations to Improve Employment Opportunities: Employment is a fundamental and valued part of adult life for Virginians with and without disabilities. Like all Virginians, individuals with disabilities want the opportunity to work, to earn wages, to pay taxes, to purchase goods and services in their communities and to become self-supporting citizens. Individuals with disabilities have the ability and desire to seek employment in community settings that provide opportunities to earn competitive wages and benefits, that encourage the individual to reach his/her maximum potential, and to be treated as equal members of the Commonwealth’s workforce. For individuals with disabilities who choose employment, a full continuum of employment options and supports need to be available. Implement Employment First in Virginia with the necessary resources to provide employment as the first option offered in the development of an individual’s day services plan but not the only option. Enhanced funding for job discovery is necessary to adequately fund a true Employment First policy with informed choice. Ensure that the full continuum and array of employment options are available in any waiver redesign to ensure an individual’s right to true choice. Ensure that Individual and Group Supported Employment billable services are fully aligned with those of the Department of Aging and Rehabilitative Services (DARS). Although we have achieved significant advances through advocacy over the last few years, there are still significant inconsistencies that make it difficult for providers of employment services to provide supported employment to individuals funded by Waivers. For example, Employment Specialists need to be able to bill for travel time to and from employment sites especially in rural areas. Resolve the issue of who bills: when a personal attendant is present at all times to support a client and the client is also receiving job development, job placement, and job coaching and/or follow-along services. Currently, only one provider can bill for the same period. When there is a multidisciplinary team meeting of several waiver service providers and the employment services provider is required to attend. Include benefits analysis and work incentives planning and assistance as a billable service under employment services. Ongoing work incentives planning and assistance should be available to individuals on a long-term basis if needed. Travel needs to be a waiver service versus a Medicaid State Plan Option (SPO) service especially for individuals who are employed and funded by the waiver. Currently, waiver recipients in supported or competitive employment can’t receive SPO transportation services unless the supported employment specialist is

present at the job site at drop off or pick-up and bills for employment services. Medicaid SPO transportation availability has to be linked to a Medicaid billing. It is a true “medical model”. The cap of 780 units of service needs to be eliminated to allow flexibility for individuals to participate in both day support or prevocational services and supported employment. Supported Employment is an hourly unit while day support and prevocational services are multi-hour units. Day support or prevocational service time should not have to be reduced for job discovery, job development or job coaching time. This is a significant disincentive to encourage individuals to discover and experience employment opportunities. The wait time for ISAR changes approval does not work for supported employment. Supported employment ISAR changes must be automatic or “deemed approval” when a job is pending for an individual. When an individual secures a job and an ISAR change needs to be approved (i.e. add more hours for job coaching), an employer is not going to wait for 5-8 weeks and the job will be lost. Approvals for Individual Supported Employment should not require specific schedules of support. Supported employment is based on the Employment Specialist time not consumer program time. Recommendations for Resource Allocation: We recommend that Virginia adopt a resource allocation methodology that is consistent with person-centered planning and takes into account the real cost of providing services. We are concerned that a SIS-based resource allocation will fail to account for the actual costs of providing services resulting in people not receiving the services they need to be safe and integrated in their communities. Following are the concerns that we shared during our stakeholder interview and clearly articulated by our interview colleague and member Steve Keener, COO and General Counsel, L’Arche Greater Washington D.C. SIS scores do not correspond reliably to the cost of providing services. The SIS is an assessment tool that was developed to score the overall intensity of supports needed by a person with disabilities to succeed in various settings. SIS scores, however, do not correspond reliably with the cost of providing services, because they do not directly measure staffing needs, which is the primary driver of the cost of providing services. For each activity of daily life, SIS scores vary based on frequency, daily support time, and type of support needed. The problem with using the SIS to allocate funding is that a low or high SIS score does not reliably indicate (1) whether professional support should be continuous or intermittent and (2) whether professional support can be shared with others at the same time. Because the SIS does not answer critical questions related to staffing, we are concerned that individual budgets determined by a SIS score will not adequately reflect the cost of providing services. SIS scores vary based on factors not directly relevant to service costs. To illustrate how the SIS does not correlate with the cost of providing services, an example is helpful. John and Melissa are supported in their homes with services funded by Medicaid Waiver. Due to safety and wellbeing needs, John and Melissa both are unable to be left alone and require continuous care that they share with their housemates when they are not at work. Because professionals spend the same amount of time supporting John and Melissa in their homes, the cost of providing

services is the same. Applying the SIS, however, John and Melissa have significantly different scores. Taking one of the assessed activities for example, John needs significant help getting dressed. His SIS score of 8 for this activity reflects that he is physically assisted (4 points) at least once per day (3 points), and the clothing assistance takes one hour daily (2 points). Melissa, on the other hand, has a score of 5 for dressing, because she needs only verbal support (2 points) a few times a week (2 points) for less than 30 minutes per day (1 point). If SIS scores determine funding, Melissa may be allocated a smaller budget than John. The provider's cost of supporting Melissa, however, are no less. Using the SIS to determine individual budgets may result in John being overfunded or Melissa being underfunded. The SIS does not ask the critical cost-related questions. The main concern with the SIS is that it does not adequately identify whether a person can safely and appropriately be alone. The SIS addresses many support activities that are relevant to a person's ability to be alone (i.e., avoiding health and safety hazards, prevention of wandering, using the toilet), but the scores for these areas are then combined and tabulated with numerous other factors that may be irrelevant to the key question of whether a caregiver is needed at all times or only intermittently. If SIS scores are applied in a mechanical way without attention to critical questions that directly determine staffing levels, funding irregularities will happen frequently. Inconsistent application of the SIS will result in funding disparities. In addition to the SIS being unable to accurately predict costs of services, we are concerned that SIS evaluations may be done inconsistently due to the varying skill of the SIS evaluator and the support team responding to SIS questions. A less skilled evaluator may apply lower SIS scores out of the incorrect notion that a person's ability to perform activities independently with a support professional present reflects an ability to perform equally well once supports have been withdrawn. Similarly, it takes critical thinking to recognize that certain supports needed intermittently must be available on a continuous basis to be effective. A high level of skill is needed from both the evaluator and the support team to arrive an accurate SIS score. We are concerned that such skill will not be applied consistently across the Commonwealth. SIS-based resource allocation causes undesirable incentives. Apart from skill, the perspectives of evaluators and support teams could lead to inconsistency in scores. Providers who have an "ability" mindset tend to think people are more able and have practices that encourage independence in performing tasks. This results in a lower SIS score, due to optimistic input from the provider and observation of the success of the provider. By contrast, providers who tend to use more intensive supports, even when not needed, will answer SIS questions accordingly and arrive at higher scores and funding levels. An unfortunate incentive of a SIS-based resource allocation system would be for providers and case managers to overstate or overuse intensive supports in order to maintain adequate funding. Recommendations: Fund allocation should be consistent with person-centered planning. The Individual Service Plan (ISP) process brings together the group of people who are most knowledgeable about the person being supported and identifies needs and goals that are

important to and important for that person. Currently, service units are authorized as an outgrowth of the needs identified in the ISP. By contrast, when SIS-based fund allocation is used, person-centered planning is normally done after the individual budget has already been determined. If the SIS is used for fund allocation, each person's ISP should be examined during the allocation process to ensure that funding will be adequate to meet support needs. Levels of service should be addressed by asking key questions directly. The key questions that drive the cost of providing services are related to staffing. Those questions are: (1) Can the person be alone without a support professional present? (2) If the person can be alone, what intermittent support is needed? (3) Can the support professional be shared with others needing support? (4) Are multiple professionals needed? If the SIS is used as a part of a resource-allocation model, these critical questions should also be asked of people supported, their guardians, and their support teams; and the answers to these questions should be weighted heavily in determining funding. Service rates should be cost-based. Costs of providing services can readily be calculated based on the staffing level and geographic location. For example, a residential provider supporting three people who need continuous support from one professional during non-work hours seven days per week will need three to four full-time direct support professionals and one manager. Staffing hours can then be multiplied by appropriate wages for the geographic area, and additional amounts should be added for general and administrative costs. This calculation should also take into account ongoing costs during hospitalizations and vacations when the provider cannot be reimbursed. The total cost is then divided by the number of people supported to arrive at a standardized reimbursement rate. Similar calculations can be done for vocational and day support services. If cost-based rates are not used, support will often be inadequate and provided by underpaid professionals who are exhausted from working multiple jobs in order to make a living wage. If the SIS is used to allocate funding, a cost-based analysis should also be performed to ensure that the results of the SIS process meet needs in a realistic way. There should be an appeal process that is independent, easy to navigate, and rarely needed. Whatever system is used to determine funding for individual budgets, it is important to have an appeal process that is administered by people who are independent from the agencies who have an interest in controlling costs. The appeal process should also be easy to navigate, so that people receiving support, their guardians, and providers can request a review without administrative hoops and can receive a timely resolution before funding shortfalls impact services. Finally, a robust appeal process should not be relied on to catch errors inherent to the funding allocation method used. We are concerned that a SIS-based approach will frequently result in underfunding. Even well-administered appeals can be time-consuming, stressful, and expensive. If the SIS-based approach is adopted, it should be augmented by practical and concrete considerations that ensure that the costs of services are met, so that appeals are rarely needed.