



*Presentation to the
Joint Commission on Health Care
Behavioral Health Care Subcommittee*

**Systems Reform for Persons with
Intellectual or Developmental Disabilities**

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President
May 17, 2011



Who We Are

- Since 1955, advocating for persons with intellectual and developmental disabilities and their families
- Past successes:
 - Visibility
 - Funding for community services
 - Community homes
 - Day and work programs
 - Movement to community inclusion

The Arc of Virginia Local Chapters

The Arc of Augusta	The Arc of North Central Virginia	The Arc of Rockbridge
The Arc of Central Virginia	The Arc of Northern Shenandoah Valley	The Arc of Smyth County
The Arc of Eastern Shore	The Arc of Northern Virginia	The Arc of South Hampton Roads
The Arc of Halifax	The Arc of the Virginia Peninsula	The Arc of Southside
Hanover Arc	The Arc of the Piedmont	The Arc South of the James
The Arc of Harrisonburg & Rockingham	The Arc of Greater Prince William	The Arc of Warren County
The Arc of Lenowisco	The Greater Richmond ARC	The Arc of Greater Williamsburg
The Arc of Loudoun County	Arc of Rappahannock	
The Arc of New River Valley	The Arc of Greater Roanoke Valley	



Consistent Public Policy Direction

"Community For All"

- All persons with ID or DD can live successfully in the community if needed supports are provided
- No one with an intellectual or developmental disability should live in a large, segregated institution
- Transition state ID training center residents to community care
- Eliminate the ID and DD waiting lists consistent with legislation passed unanimously at the 2009 General Assembly session
- Provide strong state oversight of community programs



Where Are We Now?

Five State ID Institutions

	Census	FY12 Budget
Central Virginia Training Center	385	\$79.1 M
Northern Virginia Training Center	160	\$36.4 M
Southeastern Virginia Training Center	126	\$22.1 M
Southside Virginia Training Center	246	\$69.4 M
Southwestern Virginia Training Center	186	\$25.4 M
Total	1,103	\$232.4 M

Average cost per resident: \$210,700



Where Are We Now?

Community Care

- CSB Data: Over 35,000 persons served in FY10
- HCBS ID/DD Waiver Data:
 - Intellectual Disability Waiver
 - 8,412 current ID Waiver slots
 - 4,400 receiving congregate care
 - Total cost of ID Waiver: \$485 million
 - Developmental Disability Waiver
 - 584 current DD Waiver slots
 - Total cost of DD Waiver: \$15 million
- Public School Data (2008) - The pipe line:
 - 10,062 students with intellectual disabilities
 - 1,103 students with "Severe Disability"
 - 3,048 students with "Multiple Disability"
 - 8,448 students with Autism
 - 22,661



Looking Ahead: Key Issues

- State ID Institutions Future
- Waiting List Response
- DOJ Response

State ID Institutions Future

- Transition to community care
- Twelve states have no state ID/DD institutions
 - District of Columbia (1991)
 - New Hampshire (1991)
 - Vermont (1993)
 - Rhode Island (1994)
 - Alaska (1997)
 - New Mexico (1997)
 - West Virginia (1998)
 - Hawaii (1999)
 - Maine (1999)
 - Minnesota (2000)
 - Indiana (2007)
 - Oregon (2009)
 - Michigan (2010)
- Alabama will be added this year
- Nine other states have one facility, all with less than 140 people
- Cost of community care in Virginia for those utilizing congregate care (community homes) is half that of state institutional care
- Other states have reprogrammed institutional savings to address waiting lists

State ID Institutions Future

- There is no special class of Virginia institutional residents who can not be served in community settings; thousands of persons with equivalent medical and behavioral needs are now being served in Waiver-funded community homes or within their family home
- The state institutional model is outdated by 40 years. Why? They are too expensive to operate and maintain - plus they deny basic civil rights



Waiting Lists

Intellectual Disabilities (ID) Waiver Waiting List

	Approved Slots	Urgent	Non-Urgent	Total Wait List
May 7, 2009	8,052	2,478	2,270	4,748
May 7, 2010	8,162	2,893	2,418	5,311
May 2, 2011	8,412	3,149	2,562	5,711

- Despite adding 360 slots in the last two years, the waiting list has increased by 963
- Connection between high state ID institution costs and Virginia's ability to fund Waiver slots



Waiting Lists

Developmental Disabilities (DD) Waiver Waiting List

	Total Wait List
May 7, 2009	643
May 7, 2010	891
May 7, 2011	1,118

- Waiting list has increased by 475 in the last two years



DOJ Response

- DOJ findings validated The Arc's decade-long position that everyone with ID can be served in the community if provided adequate supports and services
- Pleased with administration and legislature for funding support for community crisis stabilization capacity
- Opportunity for Virginia to move from its institutional past to embrace community inclusion
- Not breaking new ground:
 - Over 1,000 successful Virginia discharges over the past 30 years
 - Other states have successfully done closures



Systems Reform Process

- The Arc believes successful institution to community transition for individuals should have the following elements:
 - Overhaul Waiver to achieve real ICF/DD equivalency - add missing services
 - Overhaul Waiver payment structure including built-in inflation adjustments
 - Develop meaningful Individual Support Plans (ISPs) for all training center residents
 - Upgrade state oversight and protection in all settings
 - Establish ID trust fund to protect and redirect \$232 million Training Center operational funds and future land sales to community care
 - Initiate assessment of existing community programs to ensure "best practices" with goal of enhanced community integration



Systems Reform Process

- ID/DD is a core state responsibility
- Systems reform is a bigger opportunity for Virginia than just reaching a settlement agreement with DOJ
 - Use it to drive institution to community shift
 - Use it to guide ID facility planning called for in budget amendment language adopted at the 2011 session
 - Use it to address waiting list dilemma
 - Use it to soften impact of aging caregivers
 - More than 17,000 persons in Virginia with ID/DD living with caregivers who are over 60 years of age
 - Use it to reform Virginia's ID/DD Waivers in pending budget amendment language calling for Waiver study
 - Funding system drives the look of community programs
 - Overhaul payment system to address significant medical and behavioral issues
 - Avoid build-up of community mini-institutions
 - Build inflation/COLA mechanism
 - Use it to prepare for growing Autism numbers
 - Use it to prepare for Medicaid changes
- Systems reform offers historic opportunity for Virginia to move to a 'Community for All' approach

