South Carolina Department of Disabilities and Special Needs

House Legislative Oversight Committee Healthcare and Regulatory Subcommittee
October 10, 2017

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State Director

Agenda

- Finances
  - Agency Finances
  - Administrative Costs
  - Innovations Related to Potential Medicaid Changes
- Governance/DDSN Organizational Structure
- Services (DDSN and Provider Network)
- Turnover Rates
- Provider Oversight – ANE allegations

SC Department of Disabilities and Special Needs

Finances

- Agency Finances
  - Expenditures
  - DDSN Funding
    - Mission in Relation to Providers
    - Mission Strategy, Planning, Execution, and Accountability
    - Contractual Relationship with Providers
    - Directives Related to Funding
  - Room and Board
- Administrative Costs
  - Direct and Indirect Costs
- Innovations Related to Potential Medicaid Changes

SCDDSN Total and State Expenditures

Total and State Expenditures for Fiscal Years 2017, 2016 and 2015

Program/Title	FY 2016-17 Expenditures		FY 2015-16 Expenditures		FY 2014-15 Expenditures	
	TOTAL	General	TOTAL	General	TOTAL	General
I. Administration	$ **6,875,549**	$ 4,325,212	$ **6,146,063**	$ 4,063,329	$ **6,208,162**	$ 4,066,424
II. Program & Services:						
II. A. Prevention Program	$ **11,991,131**	$ 3,934,300	$ **10,366,281**	$ 3,434,300	$ **9,666,376**	$ 2,934,300
II. B. Intellectual Disabilities - Family Support Program	$ **173,038,597**	$ 65,598,921	$ **155,399,994**	$ 75,536,933	$ **152,589,797**	$ 55,824,647
II. C. Autism Family Support Program	$ **18,464,256**	$ 7,416,667	$ **17,149,228**	$ 9,508,157	$ **16,362,607**	$ 10,530,415
II. D. Head & Spinal Injury Family Support Program	$ **18,317,081**	$ 9,963,656	$ **17,231,035**	$ 10,153,601	$ **14,606,766**	$ 6,858,471
II. E. Intellectual Disability Community Residential Program	$ **308,455,302**	$ 82,000,178	$ **290,029,688**	$ 58,163,074	$ **272,859,478**	$ 71,966,398
II. F. Autism Community Residential Program	$ **13,518,539**	$ 4,519,189	$ **20,758,405**	$ 4,798,508	$ **21,209,226**	$ 4,906,382
II. G. Head & Spinal Cord Injury Community Residential Program	$ **4,062,845**	$ 944,691	$ **3,413,491**	$ 1,042,113	$ **2,818,161**	$ 940,024
II. H. Regional Centers Residential Program	$ **68,045,706**	$ 40,555,939	$ **65,130,696**	$ 38,402,578	$ **65,245,508**	$ 37,902,960
III. Employee Benefits	$ **25,774,998**	$ 20,002,096	$ **24,943,015**	$ 19,541,194	$ **24,862,095**	$ 18,892,260
IV. Non-Recurring Appropriations:						
Lander Equestrian Center	$ **300,000**	$ 300,000	$ **-**	$ -	$ **300,000**	$ 300,000
Autism Services			$ **1,000,000**	$ 1,000,000	$ **1,150,000**	$ 1,150,000
Special Needs Park - Savannah's Playground - Myrtle Beach			$ **100,000**	$ 100,000	$ **200,000**	$ 200,000
Charles Lea Center					$ **100,000**	$ 100,000
Total Agency Expenditures	$ **648,844,004**	$ 239,560,849	$ **611,667,896**	$ 225,743,787	$ **588,178,176**	$ 216,572,281

Chart available in the notebooks, page 19 of 189.

SCDDSN FY 2018 Projected Expenditures by Program Service - Dollars

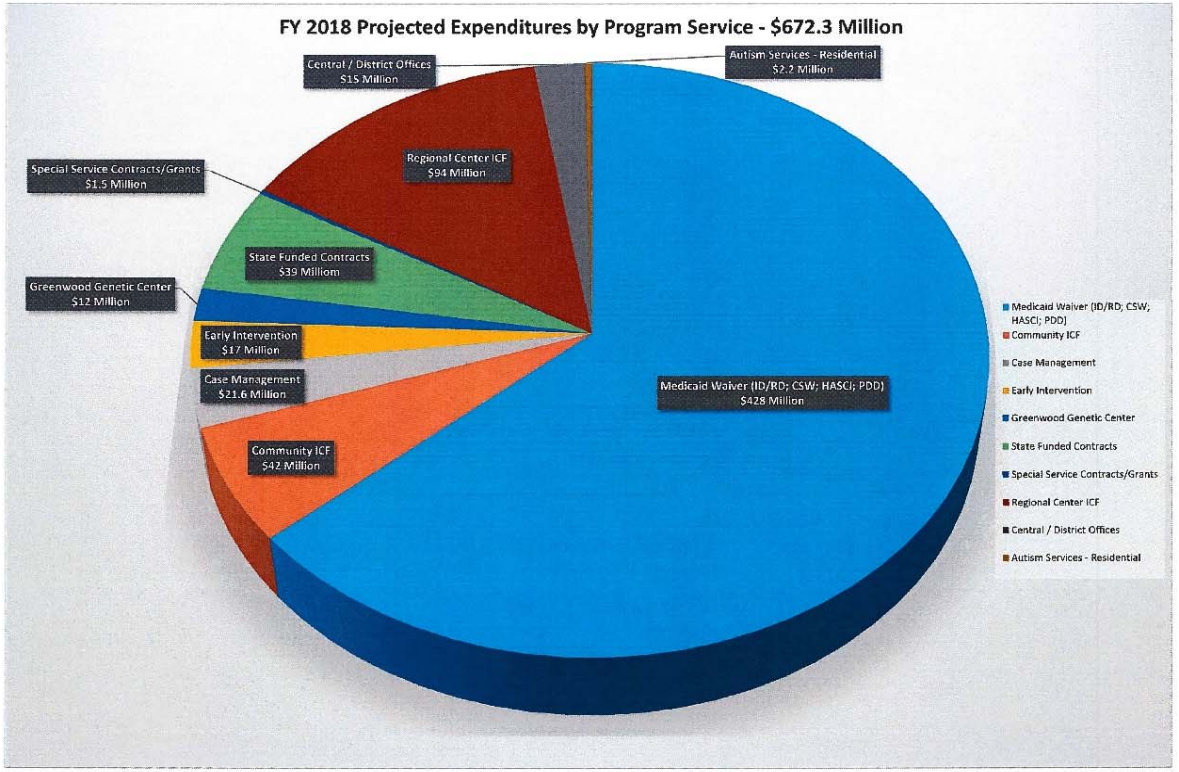


Chart available in the notebooks, page 20 of 189.

SCDDSN FY 2018 Projected Expenditures by Program Service – Percentages

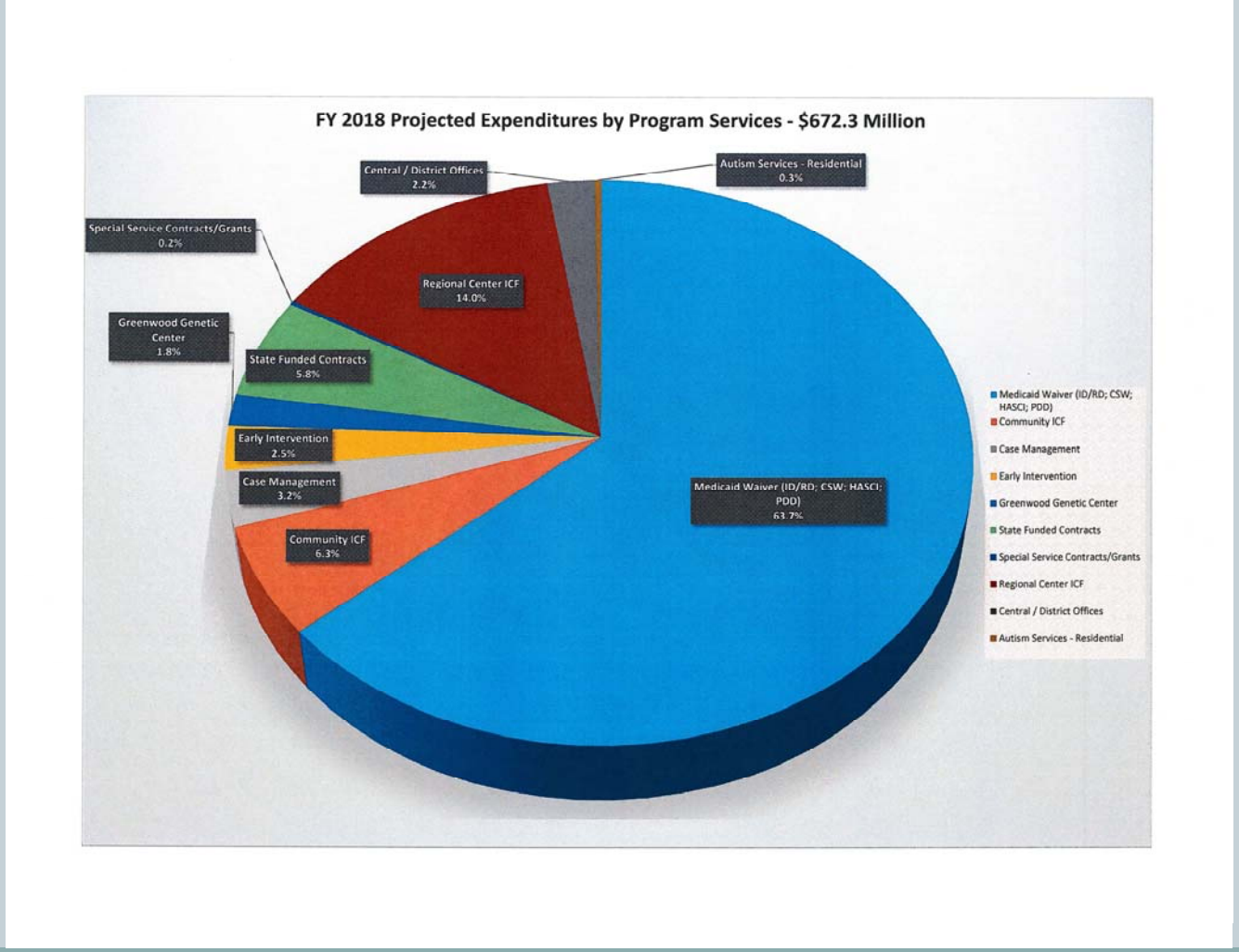
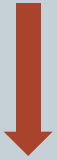


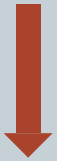
Chart available in the notebooks, page 21 of 189.

High-Level View of DDSN's Mission in Relation to County DSN Boards, QPL Providers & DDSN Direct Services

MISSION STRATEGY & PLANNING -- DDSN Establishes & Manages the Statewide Intellectual Disability Service Delivery System



MISSION EXECUTION -- Procure Service Delivery Primarily through Contracts
83.5% County Boards & QPL Contracts; 16.5% DDSN Direct Services



MISSION ACCOUNTABILITY -- DDSN Oversight & Contract Management of Providers

Full chart available in the notebooks, page 23 of 189.

MISSION STRATEGY & PLANNING---DDSN
Establishes Statewide Service Delivery System

Mission

Establish and maintain a Statewide Service Delivery System designed to meet the needs of individuals diagnosed with Intellectual Disability & Developmental Disabilities (ID/DD), Autism Spectrum Disorder, Traumatic Head or Spinal Cord Injury with a focus on consumer choice, serving consumers in the least restrictive environment, and providing a safe and healthy environment, while also being cost/effective to maximize funds available to serve consumers waiting for services.

Full chart available in the notebooks, page 23 of 189.

MISSION STRATEGY & PLANNING---DDSN
Establishes Statewide Service Delivery System

Strategy & Planning for a Statewide Service Delivery System

- Managed by 163 DDSN employees; 151 (93%) in Columbia Central Office & 12 (7%) in two field divisions at a cost of $15 million (2.2% of total agency costs);
- Operate consumer eligibility for services administered through DDSN with appeal process;
- Operate consumer eligibility for the Medicaid Home & Community Based Services (HCBS) waiver with appeal process & manage Medicaid HCBS system, to include a new centralized review process to improve consumer equity and cost control;

Full chart available in the notebooks, page 23 of 189.

MISSION STRATEGY & PLANNING---DDSN
Establishes Statewide Service Delivery System

Strategy & Planning for a Statewide Service Delivery System

- License providers serving Medicaid HCBS and DDSN consumers;
- Establish administrative and operational policies for DDSN providers serving HCBS and DDSN consumers;
- Operate a centralized information technology platform for the service delivery system;
- Provide training and technical assistance to providers;
- DDSN directly operates the Intermediate Care Facilities (ICF/IID) located in four regional centers and four residences for Autism consumers transferred from the Department of Mental Health;

Full chart available in the notebooks, page 23 of 189.

MISSION STRATEGY & PLANNING---DDSN
Establishes Statewide Service Delivery System

Strategy & Planning for a Statewide Service Delivery System

- Establish and obtain budget for the Statewide Service Delivery System through coordination with SC DHHS, Governor's Office, and Legislative approval for appropriations;
- Operate provider payment system, to include the band payment system for DSN County Boards and fee-for-service for QPL providers;
- Benefits available to all DSN Boards and private providers
  - One-time grants,
  - capital funding,
  - DDSN bills Medicaid & assumes Medicaid ineligible/audit risk,
  - 30 day residential vacancy funding,
  - 80% attendance allowance in adult day & residential.
- Band payment system for DSN Boards initiated in 1998 using a capitated model emphasizing statewide delivery service & financial stability through prospective payments Currently under review based on variety of issues.

Full chart available in the notebooks, page 23 of 189.

DDSN MISSION EXECUTION –
Procure Service Delivery Primarily through Contracts

$672.3 million - current FY 17/18 budget

Contract Providers through DSN County Boards (85%) and QPLs (15%)								DDSN		
Medicaid Waivers (ID/RD; HASCI; PDD; CSW)	Community ICFs	Case Manage-ment	Early Intervention	Green-wood Genetics	Special Service Contracts	State Funded Contracts (direct service)		Regional Centers ICFs	Autism Resident Services	DDSN General & Program Overhead
Medicaid	Medicaid	Medicaid	Medicaid	Medicaid	Medicaid	Non-Med.		Medicaid	Medicaid	Medicaid
$428 mil	$42 mil	$21.6 mil	$17 mil.	$12 mil.	$1.5 mil.	$39 mil.		$94 mil.	$2.2 mil.	$15 mil.
63.7%	6.3%	3.2%	2.5%	1.8%	0.2%	5.8%		14.0%	0.3%	2.2%
83.5%								**16.5%**		

Waiver Waiting Lists

Full chart available in the notebooks, page 23 of 189.

DDSN MISSION EXECUTION –
Procure Service Delivery Primarily through Contracts

MISSION ACCOUNTABILITY --- DDSN Oversight & Contract Management of Providers

DDSN	DDSN & DHEC	DHEC
• DDSN audit of provider financial systems, to include individual consumer accounts; • Assurance of financial condition through required annual external certified financial audit with additional agreed upon procedures; • Abuse, Neglect, and Exploitation Reporting System; • Critical Incident Reporting System; • Annual survey of participants using the National Core Indicators; • Annual licensing of residential facilities and day centers; and • Unannounced independent on-site quality reviews to measure provider contract compliance and contract outcomes.	Both inspect CRCF residences (6% total residences)	Inspects Regional Centers

Full chart available in the notebooks, page 23 of 189.

DDSN Contractual Relationship with Providers

- DDSN contracts with individual providers.
  - Public locally based DSN Boards established in State Statute
  - Private providers
- The contract language requires that all providers comply with all DDSN Directives and Standards.

Provider contract amounts available in the notebooks, pages 44 - 105 of 189.

DDSN Contractual Relationship with Providers

- Provider contracts require that the provider comply with the terms of the Fixed Price Bid solicitation.
  - Assurance 6.4 of the solicitation requires: ”Case Management shall be provided in compliance with all of the terms, conditions, applicable policy directives and standards for the provision of Case Management services and with all future terms, conditions, standards, and updates that are established by The Agency. Case Management Standards and applicable policy directives can be found on the Agency's website.”
  - Furthermore, the DDSN Special Terms and Conditions of the solicitation requires that “The Contractor shall comply with all current DDSN standards, policies, procedures, directives, and requirements for services. Failure to comply with all DDSN standards, policies, procedures, directives, and requirements for services may be considered a breach of contract.”

Provider contract amounts available in the notebooks, pages 44 - 105 of 189.

Directives Provided Related to Funding

- Funding for Services
  - DDSN Directive 250-10-DD
- Cost Principles for Grants and Contracts with Community Providers
  - DDSN Directive 250-05-DD
- Calculation of Room and Board
  - DDSN Directive 250-09-DD

Directives provided in full in the notebooks, pages 25 – 43 of 189.

Room and Board for Residential Settings

- Medicaid will not fund room and board expenses of individuals living in certain residential settings.
  - Only applies to non-Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) facilities
- Medicaid requires that the provider apply an individual's income toward the cost of room and board.

Room and Board for Residential Settings

- Most common sources of income for DDSN eligible consumers in residential settings:
  - Unearned Income
    - Supplemental Security Income (SSI)
    - Supplemental Security Disability Income (SSDI)
    - Beneficiary of parents Social Security or Civil Service benefits
  - Earned Income through employment

Room and Board for Residential Settings

- Most common room and board components:
  - Food
  - Household supplies
  - Utilities (electricity, water, sewer, trash removal)
  - Cable/Satellite television
  - Pest control
  - A percentage of general overhead, maintenance, insurance, property taxes

Room and Board for Residential Settings

- Room and board charges to consumers may not exceed the actual cost of room and board.

- For individuals receiving Supplemental Nutrition Assistance Program (SNAP), the amount of their individual SNAP benefit must be deducted from each individual's room and board charge before applying income.

Room and Board for Residential Settings

- Providers of DDSN residential services must submit room and board calculations to DDSN yearly for review and approval.
- DDSN Internal Audit reviews the implementation of room and board charges as a component of the regular audit review cycle.

Direct and Indirect Costs

Definition of Direct Costs:

- Costs incurred that are completely attributed to the care of the consumer.
- A direct cost would include the cost of the staff providing the hands on care, medical supplies and the cost of activities associated with the full care of the consumer.

Direct and Indirect Costs

Definition of Indirect Costs:

- Costs that cannot be directly assigned to the individual care of the consumer.
- These costs are general in nature and are allocated as general overhead of the organization in the care of the consumer.
- Include the salary cost of the Administrators of the organization and the support areas of the organization such as Human Resources, Bookkeeping and Information Technology.

Administrative Costs (Indirect Costs)

DDSN's administrative program expenditures are consistently very low

- FY 2012 - 1.58 %
- FY 2013 – 1.51 %
- FY 2014 – 1.34 %
- FY 2015 – 1.30 %
- FY 2016 – 1.29 %
- FY 2017 – 1.33 %

DDSN Administrative costs tables available in the notebooks, page 107 of 189.

Administrative Costs (Indirect Costs)

Local DSN Board Administrative allocations vary:

- Less than $5M budget - 10.92 % average
  - Ranging from 7.65 % - 14.06 %
- Between $5M and $15M budget – 7.46 % average
  - Ranging from 5.85 % - 13.43 %
- Over $15M budget – 7.57 % average
  - Ranging from 3.84 % - 10.25 %

DSN Board Administrative allocations tables available in the notebooks, page 108 of 189.

Anticipated Impacts of Changes to Medicaid

Any Medicaid reform must balance limits on federal spending with the removal of obligations and requirements of the states.

Letters from National Associations included in the notebooks, pages 110 – 121 of 189.

Anticipated Impacts of Changes to Medicaid

Prior Medicaid Reform Proposals:

- Converts traditional Medicaid program into a per-capita financing system
- Incorporates Medicaid expansion funding and other ACA health funds into a block grant
  - details uncertain
- Legislation intended to create maximum flexibility to states

Letters from National Associations included in the notebooks, pages 110 – 121 of 189.

Anticipated Impacts of Changes to Medicaid

Prior Medicaid Reform Proposals:

- Did not contain significant statutory reform to remove substantial Medicaid requirements which limit states ability to do the following within a block grant system:
  - target Medicaid to individuals with the highest level of need
  - expand benefits
  - respond to new requirements
- States could have the latitude to freeze or reduce provider rates
- Creates competition among spending for different populations in Medicaid.

Letters from National Associations included in the notebooks, pages 110 – 121 of 189.

Block Grant Possible Innovations

- Consideration could be given to paying cash stipends to families to cover the needs of their family member with a disability.
  - This is currently prohibited according to CMS regulations.
- Would provide families much greater flexibility of meeting needs of their loved ones without federal limitations.

Letters from National Associations included in the notebooks, pages 110 – 121 of 189.

Governance

And

DDSN Organizational Structure

DSN Board Governance

- SC Code Ann. § 44-20-375 (Supp. 2016) County boards of disabilities and special needs; establishment; recognition.
- SC Code Ann. § 44-20-378 (Supp. 2016) Composition of board; tenure.
- SC Code Ann. § 44-20-380 (Supp. 2016) Funds for county boards of disabilities and special needs.
- SC Code Ann. § 44-20-385 (Supp.2016) Additional powers and duties of county boards of disabilities and special needs.

List of all DSN Boards, statutory county, appointment ordinance, and appointing authority included in the notebooks, pages 123-124.

Potential Change Options for the DDSN Organizational Structure

- Current Structure:
  - DSN Boards are established in state statute.
    - Act as a safety net to ensure a full array of services for all DDSN eligible populations are available all across the state.
    - Currently may provide case management AND direct services to the same individual.
    - Generally operate in a geographical county or multi-county area.
    - Paid a per person, per month, prospective payment.

Potential Change Options for the DDSN Organizational Structure

- Current Structure (continued):
  - Ongoing solicitation for private providers to increase consumer and family choice.
    - Private providers may choose:
      - Services: must choose case management or direct services, cannot provide both
      - Disability and special populations
      - Geographic areas of the state
    - Paid per unit of service after services are rendered.

Potential Change Options for the DDSN Organizational Structure

- Clarify the role of DDSN as the State Agency with local contractors delivering the services.
  - Advocacy
  - Determine eligibility for DDSN services
  - Develop and implement policy for the provision and funding of services
  - Oversight - roles and responsibilities in relation to service providers
    - Oversight is on a continuum
    - Varying expectations from internal and external entities

Potential Change Options for the DDSN Organizational Structure

- Organizational Options based on other states' structures:
  - Stand alone agency, Commission Governance – current structure
  - Stand alone agency, Cabinet Governance
  - One umbrella health agency combining all health agencies, of which DDSN would be one division
    - Medicaid as part of the combined health care agency
    - Medicaid as an independent agency from other combined umbrella health agency
- Pros and Cons to each of these organizational options and varying potential impact to services to individuals and families

Services - DDSN and the Provider Network

- Service Needs Assessment
- State Funded Services
- History
- DDSN Operated Medicaid Waivers
- DDSN Residential Services
- If DDSN Had Infinite Resources

DDSN Service Needs Assessment: Waiting Lists for Services

- DDSN maintains statewide lists of individuals waiting for services by specific waiver (ID/RD and CS).
- While the list is statewide, DDSN monitors the number of people waiting and their location on the list by county.
- These lists indicate a future need for services.
- The specific waiver services needed by each individual currently waiting will be assessed just prior to waiver enrolment.

A list of the unduplicated number of individuals who are waiting for enrollment in a specific HCBS waiver by county is available in the DDSN supplemental notebooks, Tab 1.

DDSN Service Needs Assessment: Provider Budgets

- Provider Budgets
  - Each contracted provider budget includes the services and quantity of individuals served.
  - This is used for review as a reflection of the aggregate needs of all individuals served by the provider.

DDSN Service Needs Assessment: Individual Needs

- DDSN Advisory Group, Provider Meetings, Interagency Meetings and Waiver Renewal Public Forums provide individuals and stakeholders opportunities to share community and individual service needs for system growth.
- The DDSN Waiver Administration Division has begun a more sophisticated review of matching individual assessed needs to approved service levels.

DDSN Service Needs Assessment: Individual Needs

- The DDSN Post-Secondary Transition Coordinators:
  - Promote securing employment prior to exiting school.
  - Connect/contact with DDSN eligible students and families to assist them to connect with appropriate services prior to exiting school.
  - Currently, DDSN Post Secondary Transition Coordinators are reaching approximately 24% of all DDSN eligible students.

Ensuring Appropriate Services are Available

DDSN has struggled with the availability of certain services statewide, this mirrors national shortages.

- Behavioral Supports – nationwide shortage of qualified professionals in this field.
- Psychiatric Supports – statewide shortage of qualified professionals in this field.
  - Especially those with expertise in psychiatric care of individuals with ID/DD and Autism Spectrum Disorder.
  - Access to psychiatric care is even more difficult in rural areas of the state.

Ensuring Appropriate Services are Available

DDSN has struggled with the availability of certain services statewide, this mirrors national shortages (continued).

- Dental care – shortage of dentists willing to treat individuals with ID/DD, Autism Spectrum Disorder and other special needs.
- This shortage is more pronounced in rural parts of the state.

Ensuring Appropriate Services are Available

DDSN has struggled with the availability of certain services statewide, this mirrors national shortages (continued).

- In home supports such as nursing, personal care, or respite.
  - Families often have to find their own individuals to provide the services or sign on with an independent provider who provides staffing for the needs of the individual.
  - These are most often not DDSN contracted providers, they contract directly with Medicaid in most cases. DDSN does not provide the oversight for these providers.
  - It is a significant challenge for families when the scheduled person does not show up for the shift as scheduled.

Why does DDSN provide state funded services?

SC Code Ann. § 44-21-10 (Supp. 2016) et seq.

Department of Disabilities and Special Needs Family Support Services

Full copy of Section 44, Chapter 21 is included in the notebooks, pages 125-129 of 189.

DDSN State Funded Services

(not matched with Medicaid)

State Funded Services generally fall into three categories (often more than one):

1. Prevents more expensive long term services
   - Early intervention services for children
   - Family supports to avoid crisis
   - Post Acute Rehabilitation for individuals with traumatic head and spinal cord injuries
2. Needed service not billable to Medicaid
   - Specific residential settings
   - Specific programs

List of DDSN State Funded Expenditures FY 2016-2017 included in the notebooks, page 133 of 189.

DDSN State Funded Services

(not matched with Medicaid)

State Funded Services generally fall into three categories (often more than one):

3. Individual meets DDSN eligibility but not Medicaid eligible

- Awaiting Medicaid eligibility
  - Services to individuals and families on the waiver waiting list
  - Services provided immediately to children to avoid delay while pursuing Medicaid eligibility
- Determined to meet DDSN eligibility requirements but not Medicaid
  - Does not meet required nursing home level of care for individuals with a head or spinal cord injury
  - Financial disqualification for Medicaid eligibility
- Individual loses Medicaid eligibility and services are provided pending re-establishing Medicaid eligibility to prevent a lapse in services and supports.

List of DDSN State Funded Expenditures FY 2016-2017 included in the notebooks, page 133 of 189.

DDSN Expenditures

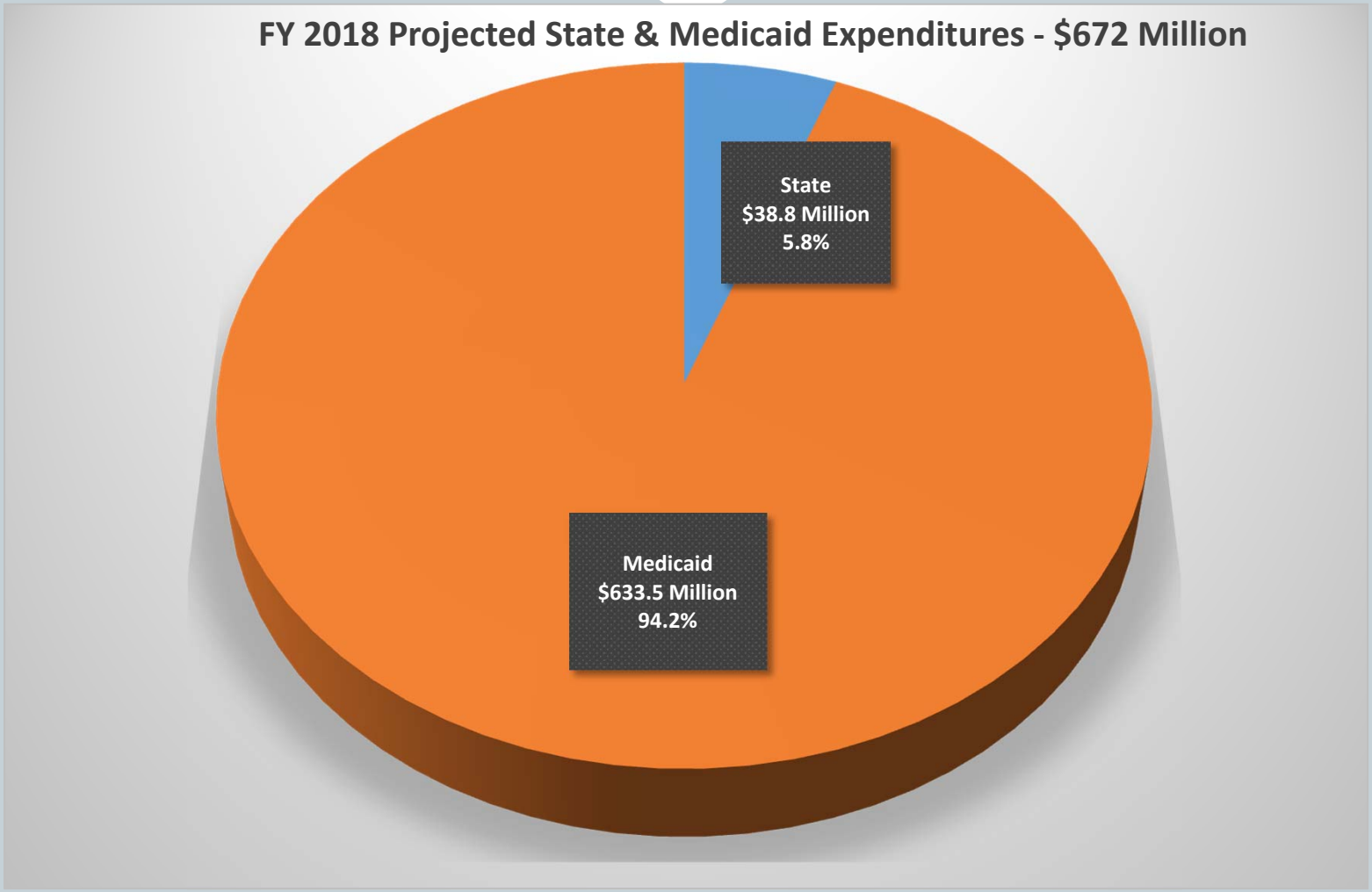


Chart available in the notebooks, page 135 of 189.

DDSN State Funded Services

(not matched with Medicaid)

Not a Medicaid Billable Service:

- **State Funded Family Support:** Provided when no other assistance is available**,** financial assistance for families who care for those with a disability to provide relief from direct, hands-on caregiving or improve an unsafe, risky or dangerous situation.
- **State Funded Community Supports:** Available to those not eligible for a Medicaid HCBS Waiver for which services are needed to avoid out-of-home placement.
- **State Funded Follow Along:** Available to those who are not enrolled in a Medicaid HCBS Waiver who have secured integrated, individual employment and require on-going supports to maintain employment.

List of DDSN State Funded Service Descriptions is included in the notebooks, page 134 of 189.

DDSN State Funded Services

(not matched with Medicaid)

Not a Medicaid Billable Service:

- **Caregiver Relief:** Group respite is provided on an alternate schedule (e.g., Saturday) to those without other available funding sources for respite.
- **Post Acute TBI/SCI:** Rehabilitation services are provided to individuals who have experienced a traumatic head or spinal cord injury who are uninsured or under-insured to address needs as soon as possible post-injury.

List of DDSN State Funded Service Descriptions is included in the notebooks, page 134 of 189.

DDSN State Funded Services

(not matched with Medicaid)

Not a Medicaid Billable Service:

- **Child Day:** Limited, specialized daytime activity program provided for children with intensive needs.
  - (Appropriations Act 2016-2017 Part 1B Section 36-J160 Department of Disabilities and Special Needs, Proviso 36.9 Child Daycare Centers)
- **Greenwood Genetics – Autism Research:** Research addressing the causes and prevention of Autism Spectrum Disorder.
  - (Appropriations Act 2016-2017 Part 1B Section 36-J160 Department of Disabilities and Special Needs Proviso 36.12 Greenwood Genetic Center Autism Research)

List of DDSN State Funded Service Descriptions is included in the notebooks, page 134 of 189.

DDSN State Funded Services

(not matched with Medicaid)

Medicaid Billable Service, individual not eligible:

- **Early Intervention:** Family training provided in-home by trained staff intended to increase family's ability to promote the developmental growth of children ages birth to three (3).
  - 40 % of children served are not currently Medicaid eligible.

- **PDD- State Funded:** Services provided per the 2006-2007 General Appropriations Act to include applied behavior analytic and case management services paid with 100% state dollars for non-Medicaid recipients.
  - These individuals meet all program requirements to receive the 1915c HCBS Pervasive Developmental Disorder Waiver service with the exception of Medicaid eligibility.

DDSN State Funded Services

(not matched with Medicaid)

Medicaid Billable Service, individual not eligible:

- **State Funded Case Management:** Services available to those who are not Medicaid eligible to gain access to needed medical, social, educational and other services.
- Used to complete the enrollment process for an individual to begin services in a Home and Community Based Setting Medicaid waiver.

List of DDSN State Funded Service Descriptions is included in the notebooks, page 134 of 189.

DDSN State Funded Services

(not matched with Medicaid)

Non-Medicaid Residential Placements:

- **Correct Care, Alt. Placement:** Specialized residential service provided to individuals involved in the criminal justice system or have other considerations requiring a more secure setting. These residential settings are not billable to Medicaid.
- **State Funded Residential (Non-HASCI):** Residential Habilitation provided to those who are not Medicaid eligible. Individuals often become Medicaid eligible after residential placement.
- **Head & Spinal Cord (Residential, Community Opportunities):** State-funded Residential Habilitation services for individuals who do not meet Medicaid eligibility requirements. This category also includes community drop-in centers for people with brain and spinal cord injury to attend for socialization experiences.

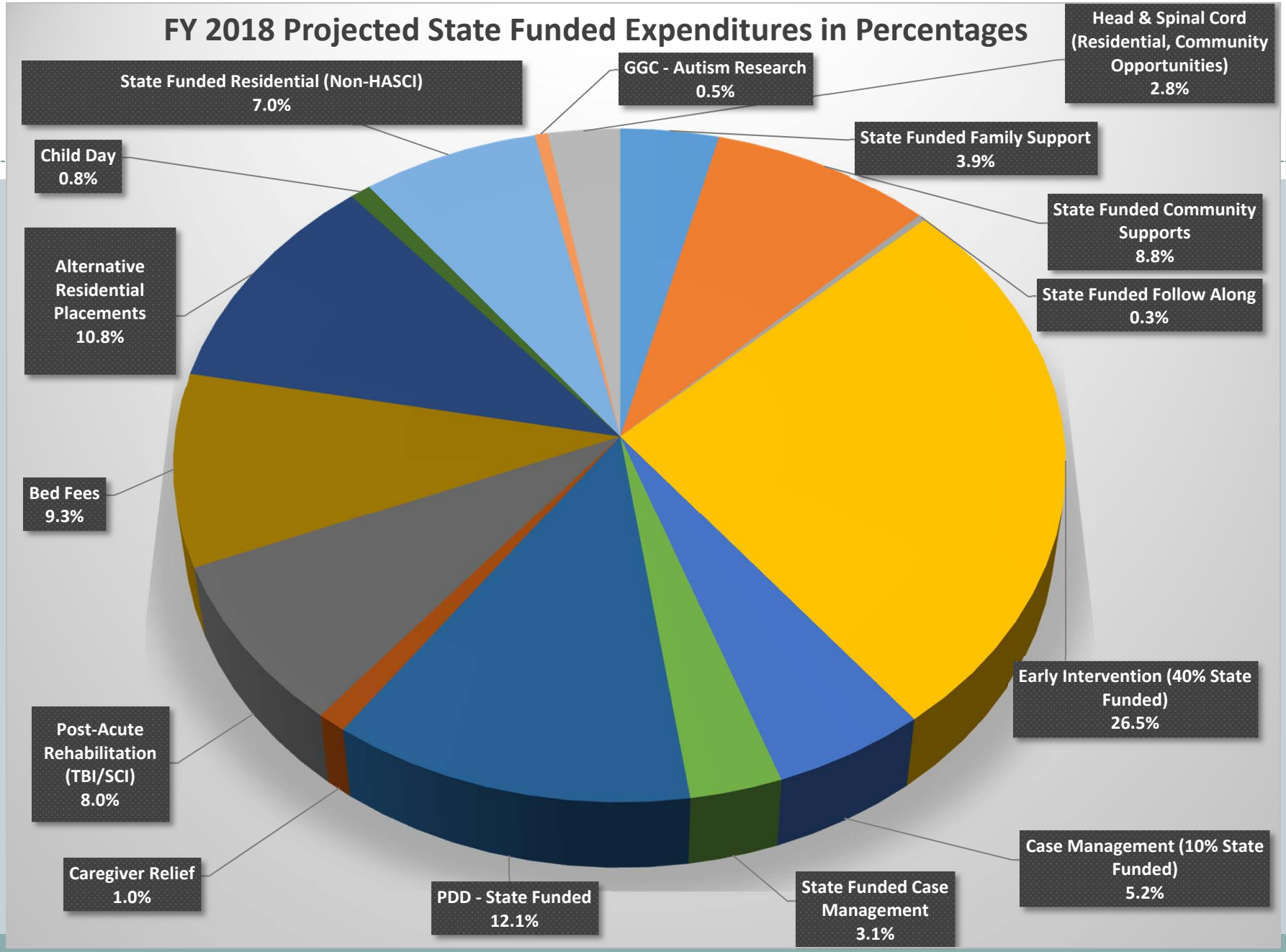
List of DDSN State Funded Service Descriptions is included in the notebooks, page 134 of 189.

DDSN State Funded Services

Bed Fees:

The federal government allows states to charge a per bed tax for hospital and nursing home beds that are provided to Medicaid recipients.

- The bed tax/fee covers some of the cost of administering the Medicaid program within the state.
- The bed fee for ICF/IIDs in South Carolina is $8.50 per day.



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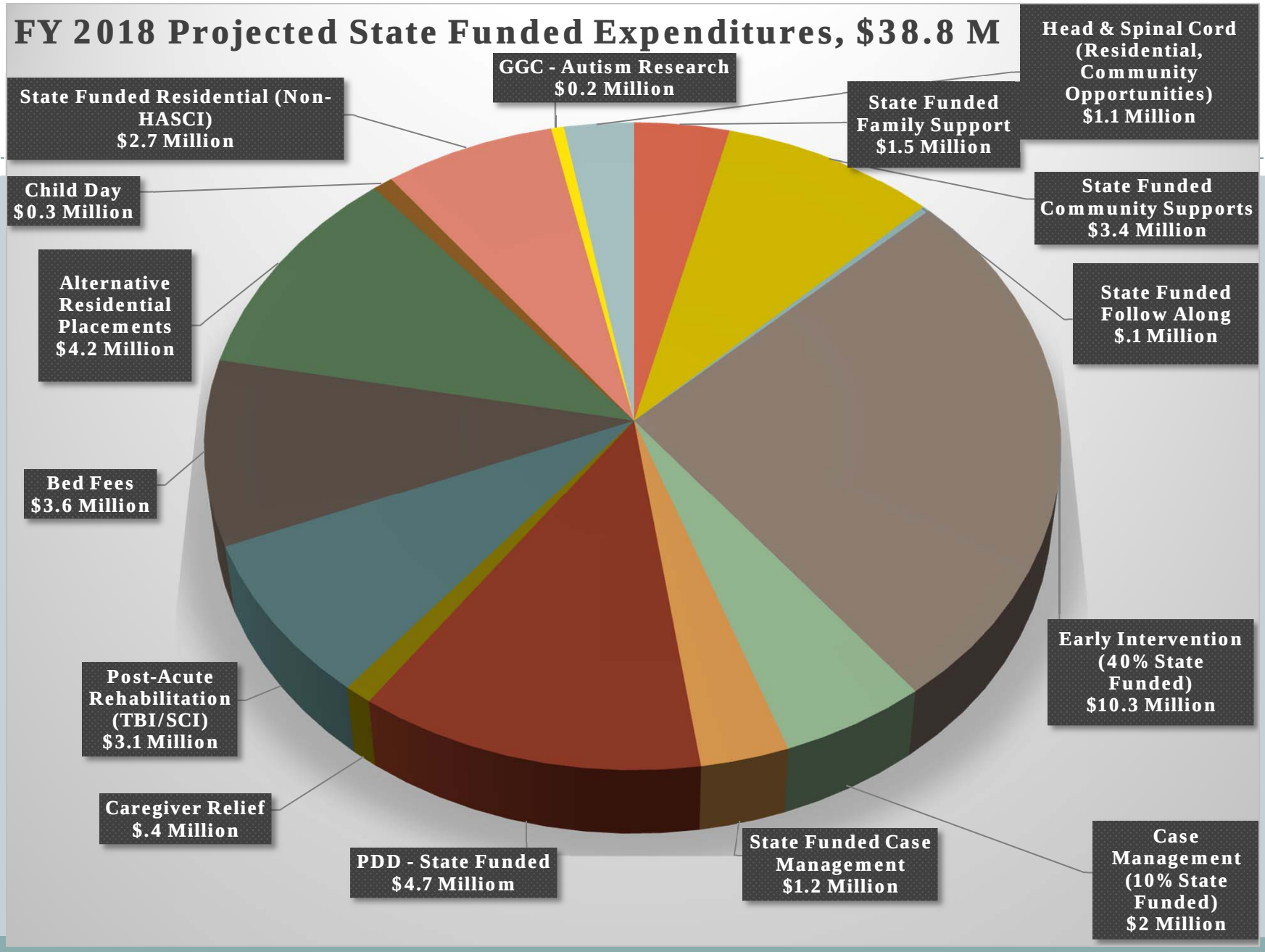


This chart is available in the notebooks, page 137 of 189.

DDSN Maximizes Medicaid Match

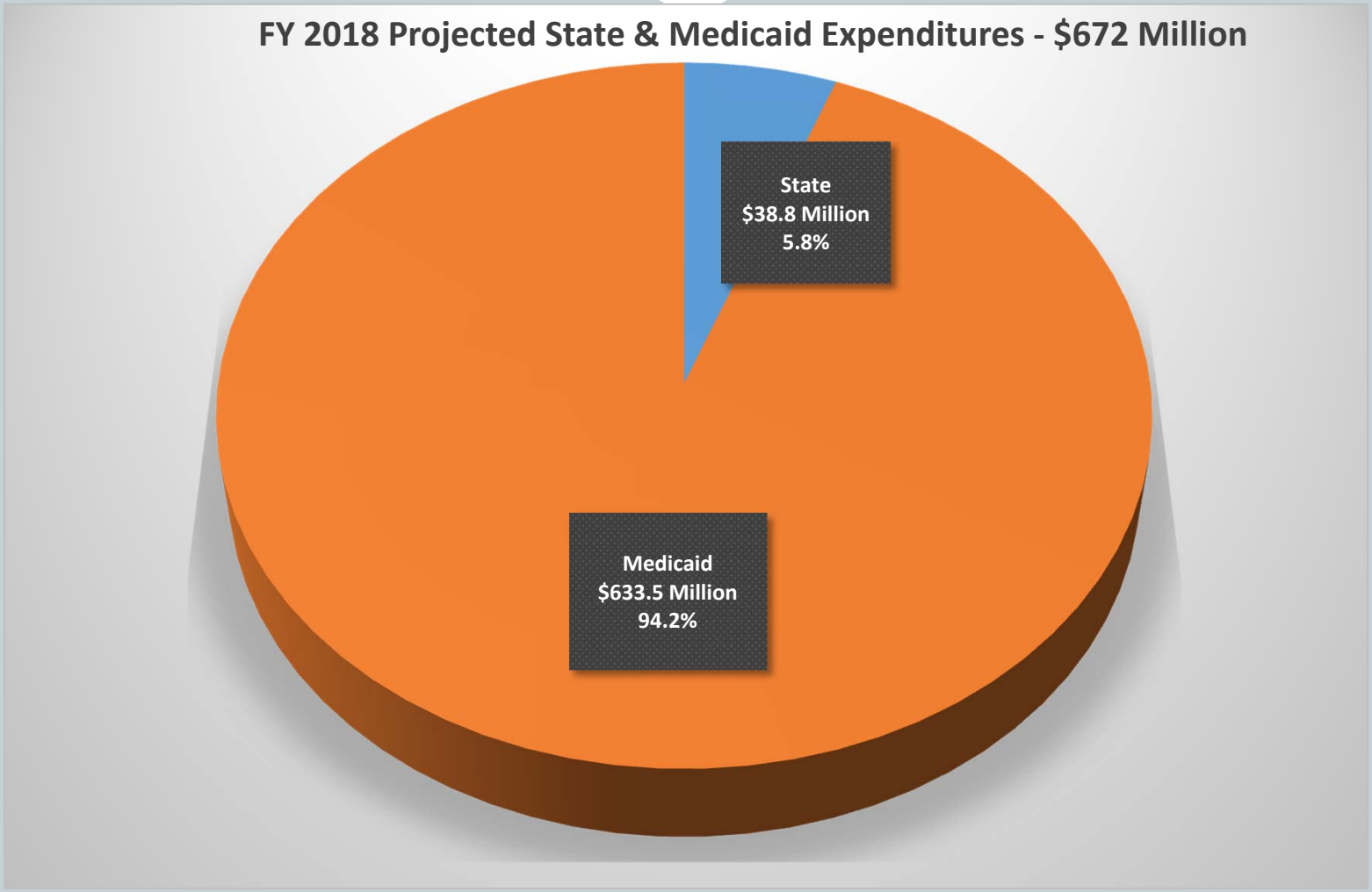
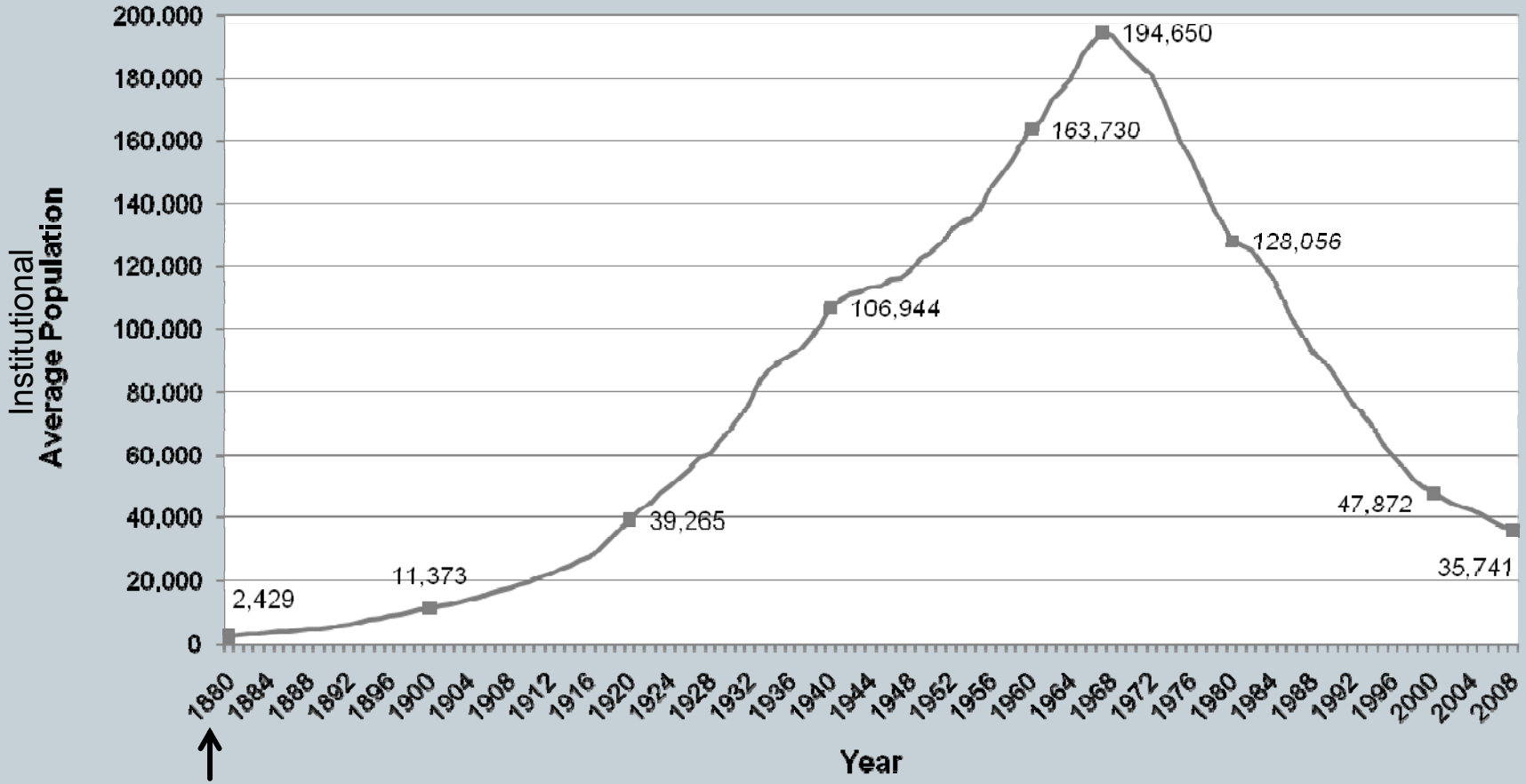
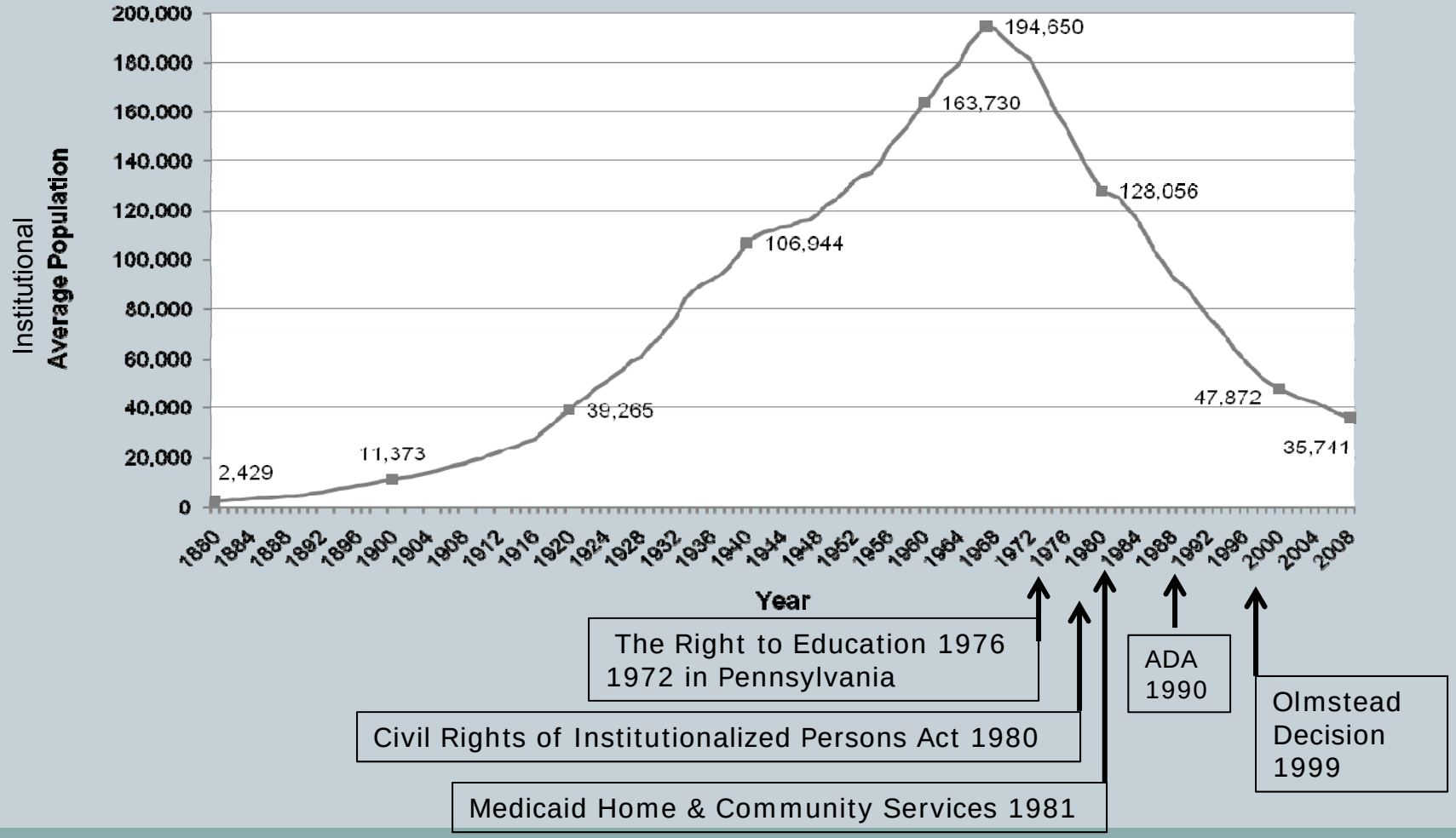


Chart available in the notebooks, page 135 of 189.

Know the History:
How has the past influenced our future?



Know the History: The Impact of Public Policy



DDSN Operated Medicaid HCBS Waiver Services

What is a Medicaid Waiver?

- The HCBS waiver program was established by Section 2176 of the Omnibus Budget Reconciliation Act of 1981 and was incorporated into the Social Security Act at Section 1915(c).
- The program was created to provide states a funding mechanism to support individuals in the community.
- This passage recognized that many individuals at risk of institutionalization could be supported in the community and many, in their own homes.

A comprehensive list of all four DDSN operated HCBS waiver services is included in the notebooks, pages 131 – 132 of 189.

DDSN Operated Medicaid HCBS Waiver Services

What is a Medicaid Waiver (continued)?

- States can elect to furnish under Medicaid, as an alternative to institutional care, an array of non-medical services (excluding room and board) not otherwise covered under the Medicaid program.
- Because the 1915(c) waivers were created to offer alternatives to institutionalization, the program regulations require HCBS to be offered only to those who are eligible for institutional placement (42 C. F.R. 440.180).
- Today, there are multiple waiver programs with varied target populations and eligibility criteria.

A comprehensive list of all four DDSN operated HCBS waiver services is included in the notebooks, pages 131 – 132 of 189.

DDSN Operated Medicaid HCBS Waiver Services

- DDSN Operates four Medicaid Home and Community Based Services waivers on behalf of SCDHHS.
  - Intellectual Disabilities & Related Disabilities (ID/RD) Waiver
  - Head & Spinal Cord Injuries (HASCI) Waiver
  - Pervasive Developmental Disorder (PDD) Waiver
    - Due to sunset December 2017
  - Community Supports Waiver (CSW)

A comprehensive list of all four DDSN operated HCBS waiver services is included in the notebooks, pages 131 – 132 of 189.

DDSN Operated Medicaid HCBS Waiver Services

- Examples of In-Home Waiver Services (availability varies by waiver type and individual assessed needs)
  - Personal care/Attendant care
  - Employment services
  - Respite care for families
  - Behavioral support services
  - Nursing services
  - Day supports
  - Adult Day Health Care
  - Private vehicle modifications
  - Environmental modifications
  - Specialized medical equipment and assistive technology

A comprehensive list of all four DDSN operated HCBS waiver services is included in the notebooks, pages 132 – 132 of 189.

SCDDSN Service Delivery

Residential Services:

- Available in the ID/RD, HASCI waivers, and as a State Plan Medicaid service ICF/IID.
- DDSN must approve all individuals receiving residential services.
- Residential services are only approved for individuals whose health, safety and welfare may be jeopardized.

A comprehensive list of all four DDSN operated HCBS waiver services is included in the notebooks, pages 131 – 132 of 189.

A list of DDSN residential setting options and descriptions is included in the notebooks. Page 24 of 189.

SCDDSN Service Delivery

Residential Services:

- In accordance with state and federal law, DDSN provides residential services in the least restrictive option possible.
- There is a hierarchy of different residential service options which vary in the level of restrictiveness.
- DDSN uses clinical data to review any individual moving to a more restrictive residential setting to maximize resource utilization.

A comprehensive list of all four DDSN operated HCBS waiver services is included in the notebooks, pages 131 – 132 of 189.

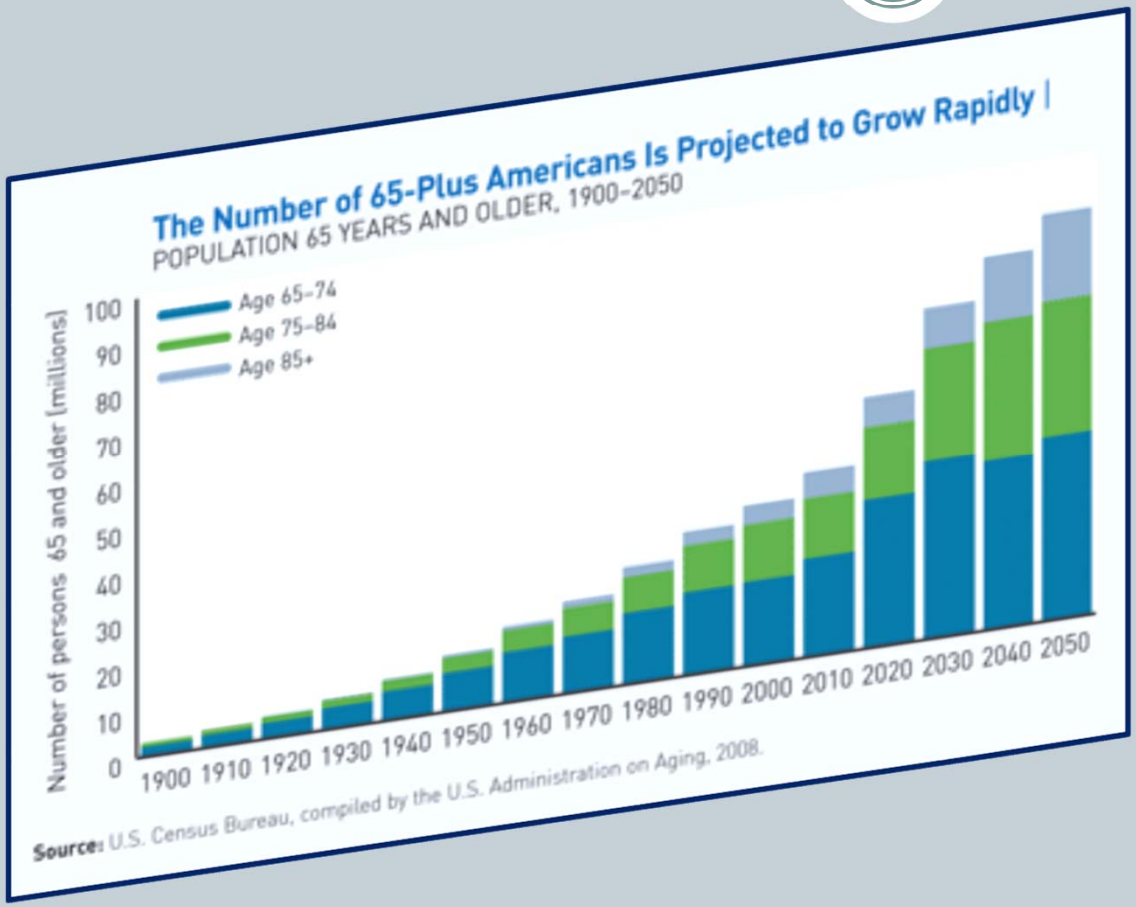
A list of DDSN residential setting options and descriptions is included in the notebooks. Page 24 of 189.

What services would DDSN offer with Infinite Resources?

If money were no object?

(1) Increase Direct Support Professionals and other staff wages

Impact of the Baby Boom Generation

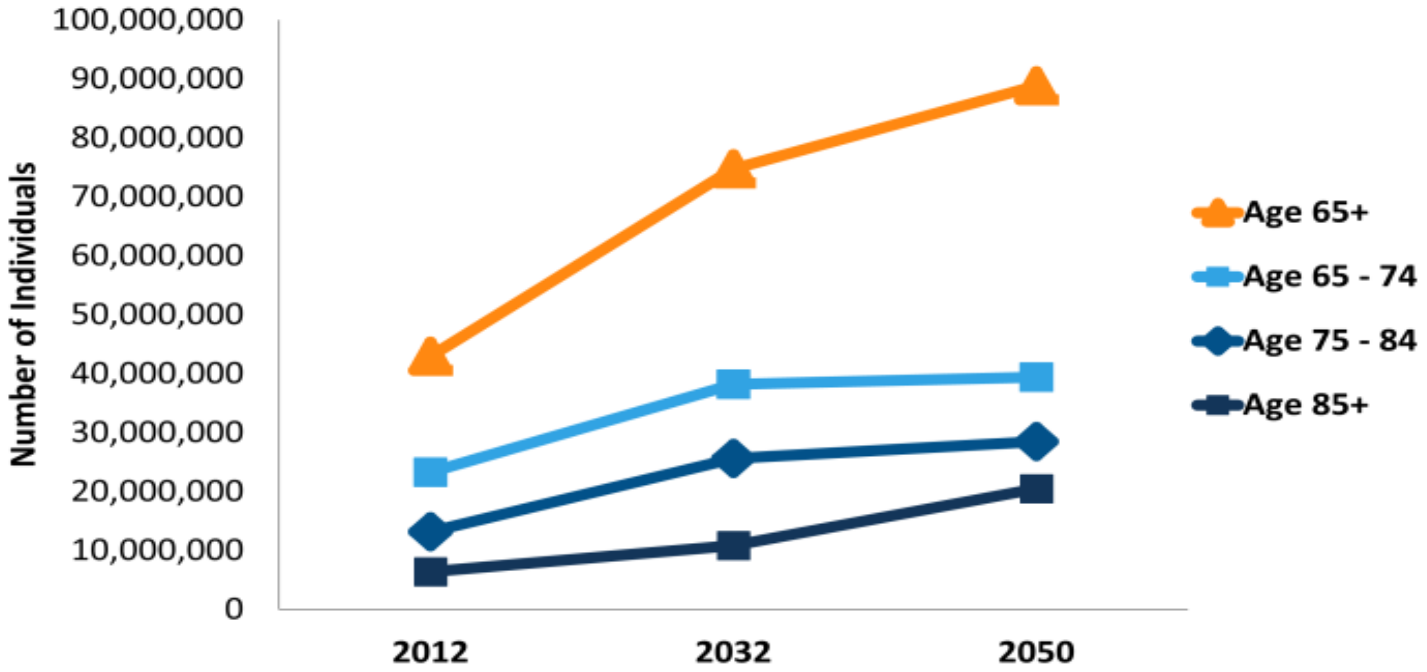


70% of Americans who reach age 65 will need some form of long-term care for an average of three years.

Stats on Aging Population

Figure 1

The 65 and Over Population Will More Than Double and the 85 and Over Population Will More Than Triple by 2050



SOURCE: A. Houser, W. Fox-Grage, and K. Ujvari. *Across the States 2013: Profiles of Long-Term Services and Supports* (Washington, DC: AARP Public Policy Institute, September 2012), http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/across-the-states-2012-full-report-AARP-ppi-ltc.pdf.

What services would DDSN offer with Infinite Resources?

(2) No waiting lists for services:

- Waiver services are not considered an entitlement service within Medicaid.
- Access to waiver services are directly dependent upon State appropriation of funds.

What services would DDSN offer with Infinite Resources?

(3) Offer residential services much more broadly:

- Residential supports are among the most expensive services.
- Individuals and families must meet strict criteria for access to residential supports and services.
- Eligibility currently based on need, not want or desire.
- Would allow more individuals to live more independently.
- Would allow families to be more proactive in planning for their loved ones.

What services would DDSN offer with Infinite Resources?

(4) Offer enhanced employment supports:

- Better coordination and supports available for youth as they approach high school graduation.
- More exposure to employment possibilities and opportunities to ensure that individuals receive experience in order to determine employment interests.
- Enhanced follow along for individuals currently employed to ensure continued employment.

What services would DDSN offer with Infinite Resources?

(5) Provide additional Post Acute Rehabilitation services:

- Rehabilitation services provided for uninsured or under-insured individuals to address needs as soon as possible post-injury for traumatic head injuries and traumatic spinal cord injuries.
- The eligibility criteria is currently set very high, additional funding would allow more people to benefit from this service and improve their overall level of functioning after the injury and life long.

What services would DDSN offer with Infinite Resources?

(6) Increased Crisis Management Supports:

- Increase access to psychiatric supports.
- Increase access to behavioral supports services.
- Additional temporary residential settings for temporary crisis management.

What services would DDSN offer with Infinite Resources?

(7) Additional Community Service Options – offer services not currently available or in larger amounts:

- Respite for families.
- Personal care and supports available in the home.
- In and out of home respite options to give families a break from care of their loved ones.
- Assistant with household needs.
  - Specific to supporting someone with a disability (ADA modifications to homes and vehicles for example).
  - Not specific such as assistance with utility bills to keep a family in their home.

What services would DDSN offer with Infinite Resources?

(8) More individualized supports:

- Consistent with the new CMS Home and Community Based Services Final Rule.
- More individualized care, one staff to one person (if needed and clinically appropriate) to lead to more individualized care tailored to person specific interests and outings.

National Measures and Benchmarks

What are other states doing well?

National Benchmarks

- What other states exemplify service to populations served by DDSN?
- How do we know? How is it measured?
  - Case for Inclusion annual report by UCP
  - State of the States in Intellectual and Developmental Disabilities – University of Colorado
  - In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities - The University of Minnesota
  - The National Report on Employment Services and Outcomes – University of Massachusetts/Boston
  - National Community of Practices for Supporting Families of Individuals with I/DD Across the Lifespan

Links to the full reports referenced are available in the DDSN supplemental notebook, Tab 3.

UCP Case for Inclusion Report

- The most comprehensive rating of state ID/DD service systems is conducted by United Cerebral Palsy (UCP).
- UCP is a national disability advocacy organization that was founded in 1949.
- UCP has been conducting annual independent assessments of states' use of Medicaid and other public supports to promote individuals with intellectual and developmental disabilities participating in all aspects of community life since 2006.

The full report UCP Case for Inclusion 2016 is available in the DDSN supplemental notebook, Tab 2.

UCP Ranking Description

- All 50 states and the District of Columbia are assessed .
- Data from twenty-five measures are compiled.
- Measures are grouped into five overarching areas:
  - Promoting Independence
  - Health Safety & Quality of Life
  - Keeping Families Together
  - Promoting Productivity
  - Reaching Those in Need

The full report UCP Case for Inclusion 2016 is available in the DDSN supplemental notebook, Tab 2.

UCP Ranking Description (continued)

- Measures were selected based upon family and advocate input on those areas most important to individuals with intellectual and developmental disabilities.
- Each measure was weighted to reflect importance.
- Data used was from other nationally recognized sources (e.g., Universities of Minnesota, Colorado, Massachusetts; National Core Indicators).

The full report UCP Case for Inclusion 2016 is available in the DDSN supplemental notebook, Tab 2.

UCP Five Major Ranking Categories

Category	Measures	Weight of All Measures
Promoting Independence	8	50%
Health, Safety and Quality of Life	5	14%
Keeping Families Together	3	8%
Promoting Productivity	5	12%
Reaching Those In Need	4	16%

The full report UCP Case for Inclusion 2016 is available in the DDSN supplemental notebook, Tab 2.

UCP Rankings Over Time

	Average	2016	2015	2014	2013	2012
Arizona	1	1	1	1	1	1
South Carolina	15	14	9	6	12	13
Southeastern Average	41	35	32	47	46	42

Southeastern Average defined by CMS SE region

The full report UCP Case for Inclusion 2016 is available in the DDSN supplemental notebook, Tab 2.

UCP Category Rankings - 2016

Category	Arizona	South Carolina	Southeastern Average
Promoting Independence	4	36	34
Health, Safety and Quality of Life	25	4	15
Keeping Families Together	1	3	27
Promoting Productivity	27	21	37
Reaching Those In Need	5	31	42

The full report UCP Case for Inclusion 2016 is available in the DDSN supplemental notebook, Tab 2.

UCP National Findings

- "All states have room to improve."
- Top performing states have no common characteristic.
  - Urban and rural
  - Wealthy and poor
  - High and low tax burden
  - High and low spenders on services
- Waiting lists for residential & community services continue to climb.

The full report UCP Case for Inclusion 2016 is available in the DDSN supplemental notebook, Tab 2.

UCP SC Findings

- SC is one of the top performing states in supporting individuals with intellectual/developmental disabilities actively participate in their communities.
- SC has been successful despite our low per person service expenditures.
- SC excels in helping individuals with disabilities remain with their families.
- SC is effective in protecting the health and safety of individuals with disabilities.
- For individuals with disabilities who are not able to remain with their families, SC needs to support more individuals in smaller living situations.

The full report UCP Case for Inclusion 2016 is available in the DDSN supplemental notebook, Tab 2.

State Performance Measures

- The University of Minnesota has been compiling statistics on state ID/DD residential services since 1990 and broadened their focus to include services provided to individuals living with their families in the mid-2000s.
- The size of the residential setting that individuals are served in is an important benchmark gauging the degree to which state service delivery systems are able to integrate individuals.
  - Facilities which serve 16 + individuals are generally considered to be institutional and not effective in including individuals with disabilities into their communities.
  - Facilities which serve 3 individuals or less are generally considered to be the most effective in including individuals with disabilities into their communities.

The full report UCP Case for Inclusion 2016 is available in the DDSN supplemental notebook, Tab 3.

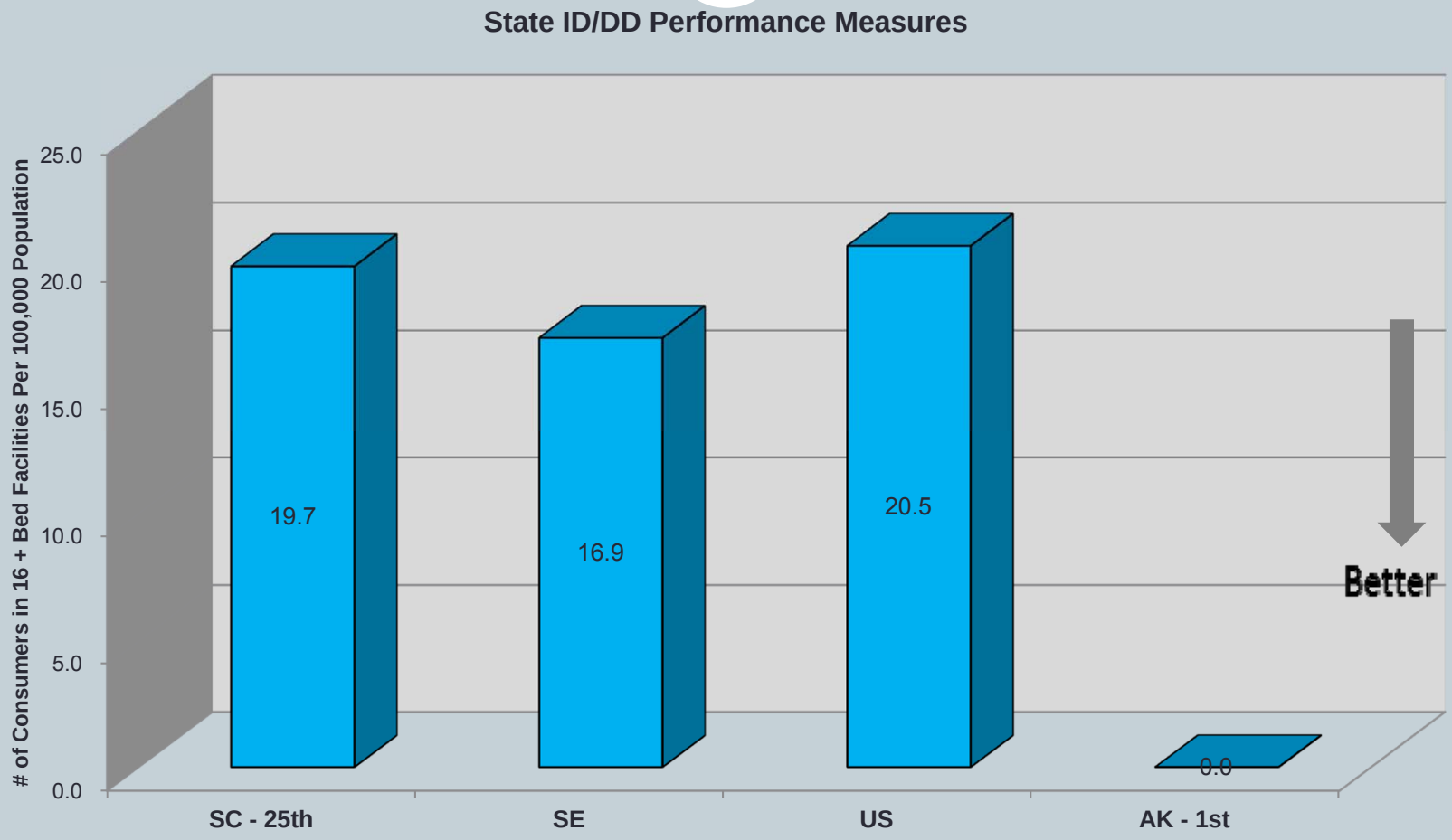
State Performance Measures

- South Carolina is slightly below the national average and slightly above the southeastern average on supporting persons in 16 + bed facilities.

- South Carolina is well beneath the national and southeastern average on supporting persons in smaller living arrangements.
  - This is due to increased cost of supporting persons in smaller settings.

Links to the full reports referenced are available in the DDSN supplemental notebook, Tab 3.

State Performance Measures



Data Source – In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends through 2014 published by the University of Minnesota

Links to the full reports referenced are available in the DDSN supplemental notebook, Tab 3.

State Performance Measures

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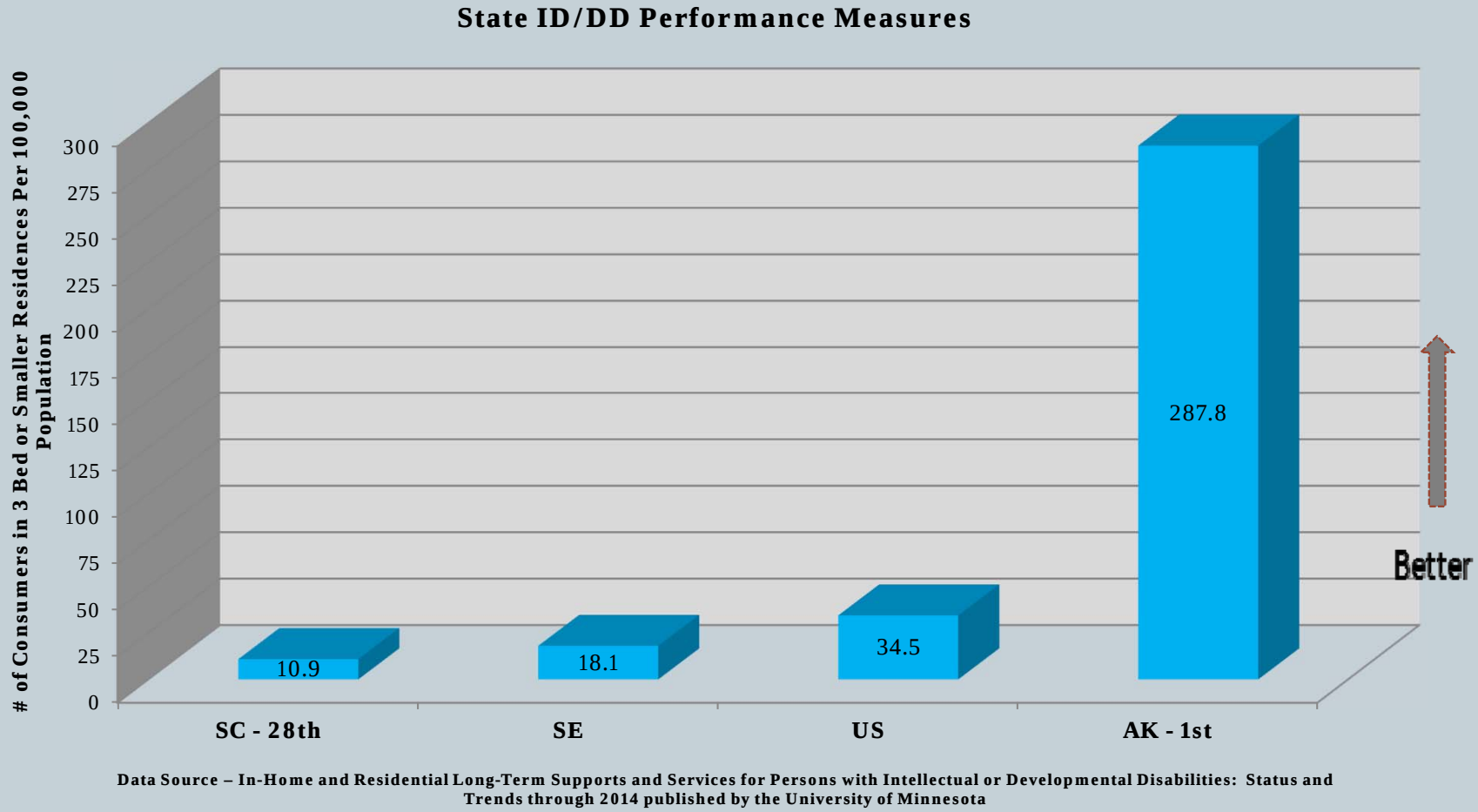


Data Source – In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends through 2014 published by the University of Minnesota

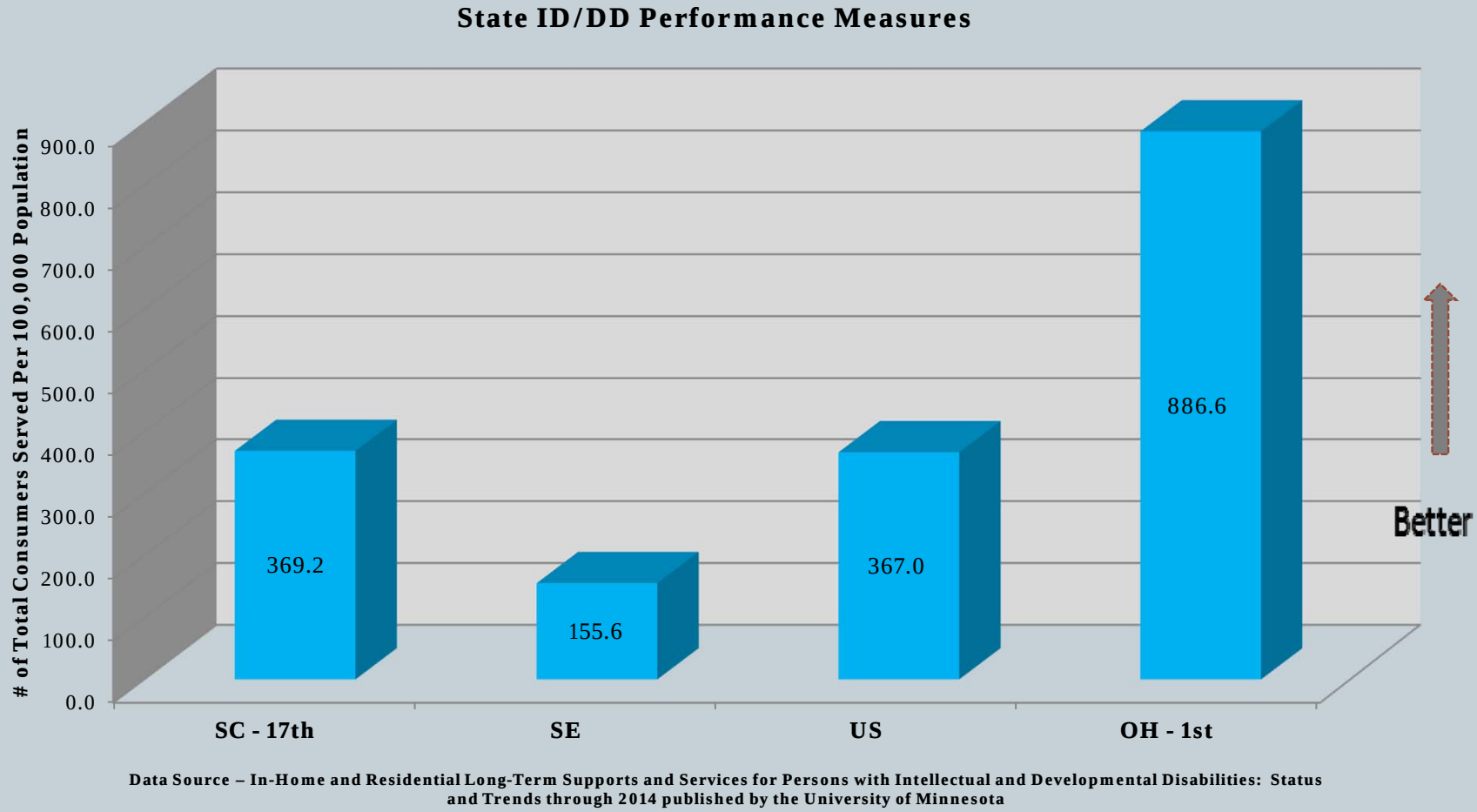
Links to the full reports referenced are available in the DDSN supplemental notebook, Tab 3.

State Performance Measures

- The number of individuals served by the state service system is an important measure of the degree to which needs are being met.
- It is generally considered preferable to serve individuals while living with family instead of removing them from the family.
  - More family friendly
  - Less expensive
- South Carolina exceeds both national and southeastern average for the number of persons they serve and the proportion of persons served while living with family.

Links to the full reports referenced are available in the DDSN supplemental notebook, Tab 3.

State Performance Measures



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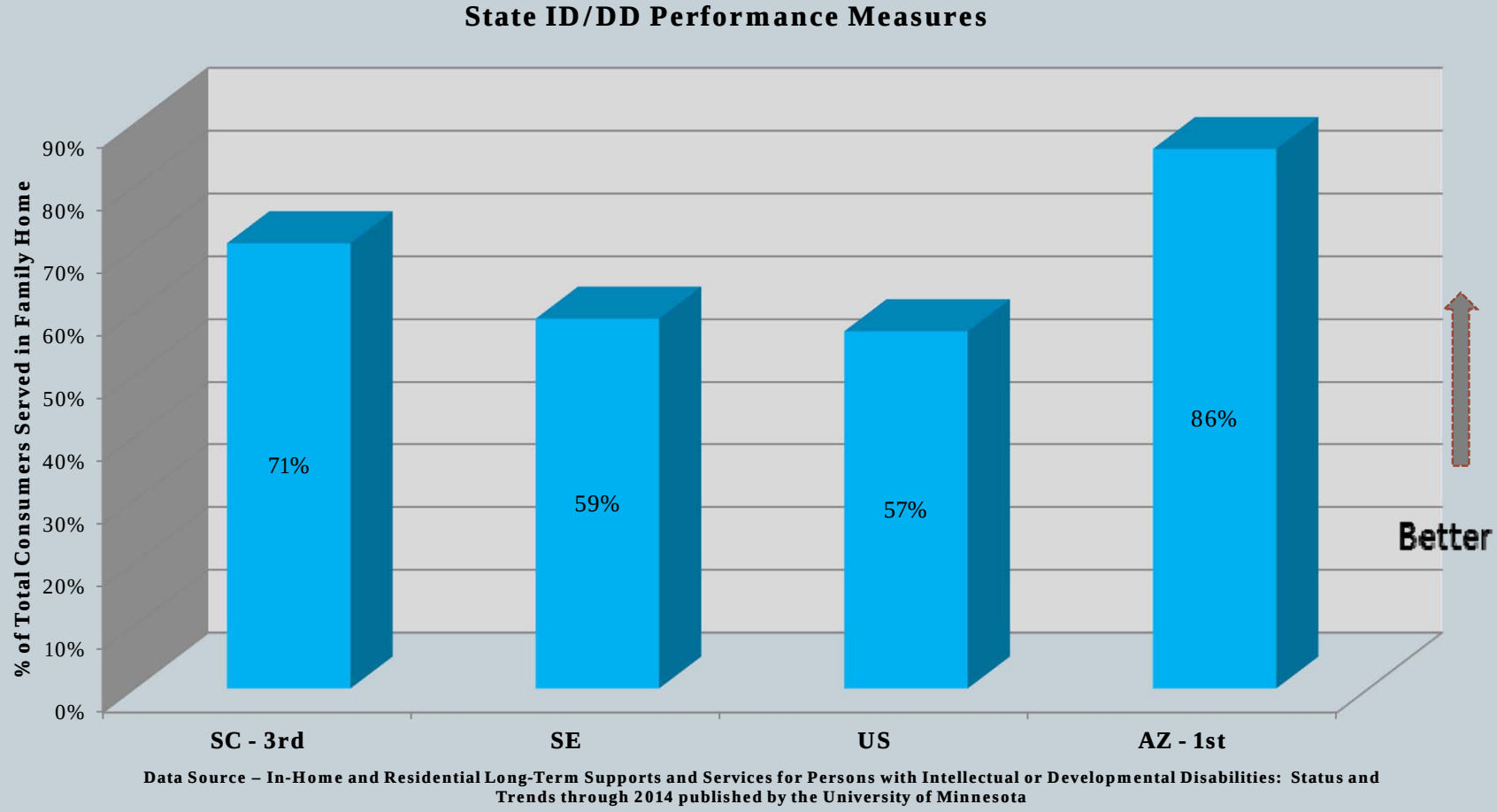
State Performance Measures



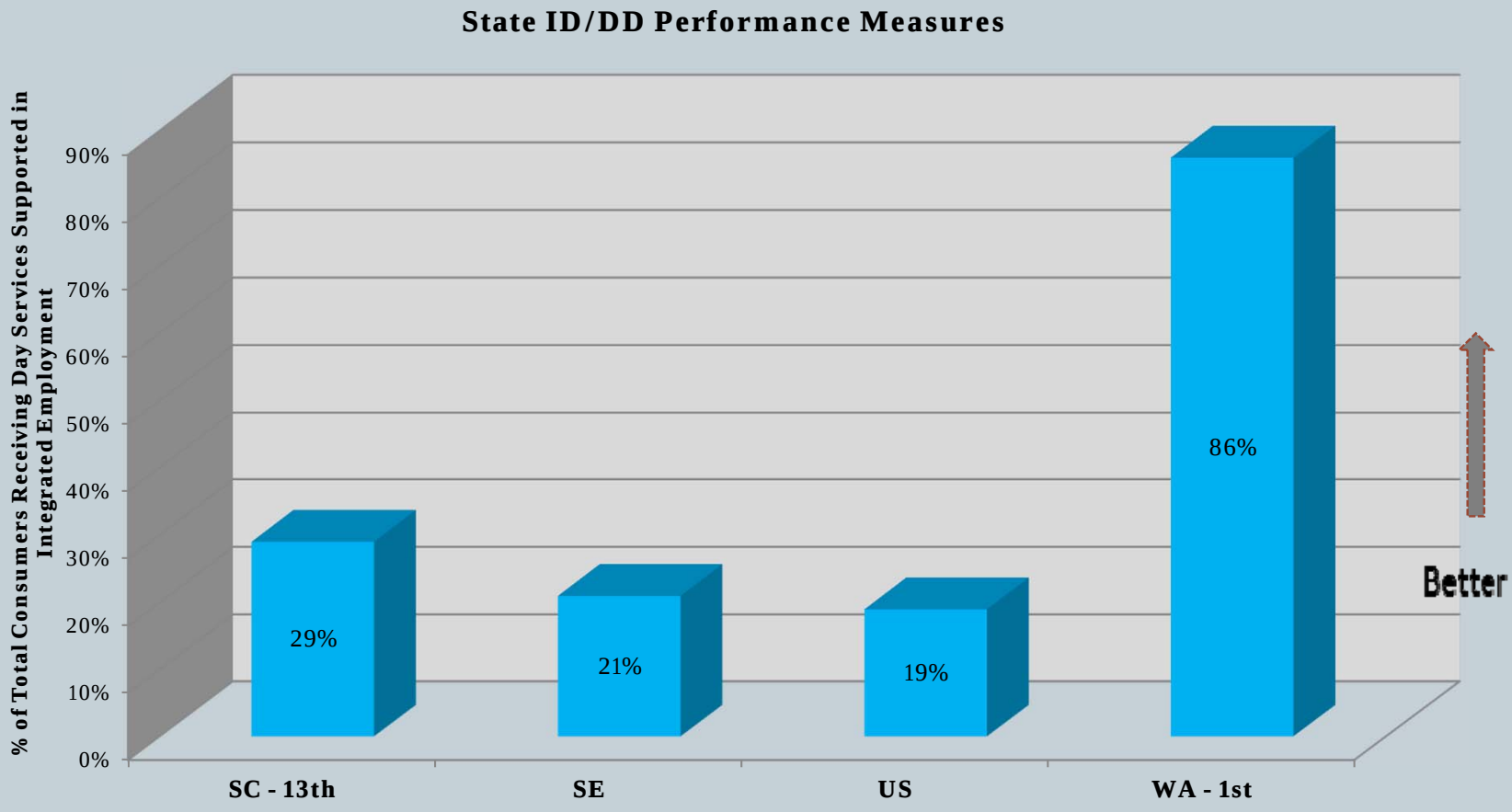
Links to the full reports referenced are available in the DDSN supplemental notebook, Tab 3.

State Performance Measures

- The University of Massachusetts/Boston has been compiling reports on the status of state employment supports provided to individuals with disabilities since the mid-1980s.
- One of the most important desires for individuals with disabilities is to be employed in a business where they can interact with others who do not have a disability.
- South Carolina exceeds both the national and southeastern average for supporting individuals in integrated employment settings.

Links to the full reports referenced are available in the DDSN supplemental notebook, Tab 3.

State Performance Measures



Data Source - State Data: The National Report on Employment Services and Outcomes 2015 published by the University of Massachusetts/Boston

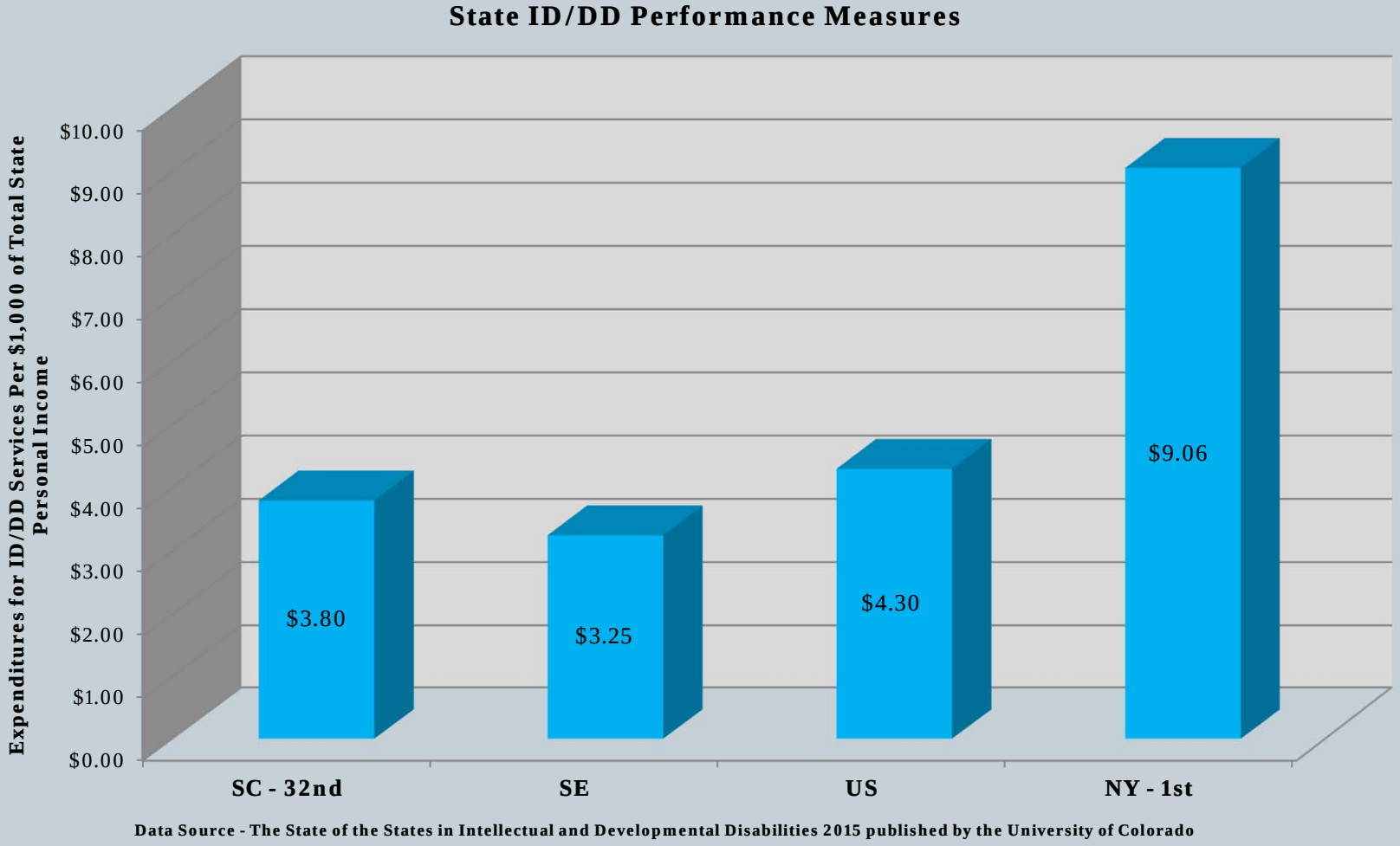
Links to the full reports referenced are available in the DDSN supplemental notebook, Tab 3.

State Performance Measures

- While the amount of expenditures devoted to supporting persons with Intellectual Disabilities is not the most important ones, it does have an impact on the quantity and quality of services that can be provided.
- The University of Colorado has been producing reports on state ID/DD expenditures since 1990.
- While South Carolina's disability system uses resources efficiently to maximize the number of persons served, it does not rank high among other states in the level of funding devoted to services for persons with intellectual disability.

Links to the full reports referenced are available in the DDSN supplemental notebook, Tab 3.

State Performance Measures



Links to the full reports referenced are available in the DDSN supplemental notebook, Tab 3.

National Best Practice Goals

- Employment
- Supporting Families

Fact sheets from RRTC Advancing Employment for Individuals with Intellectual and Developmental Disabilities are available in the DDSN supplemental notebook, Tab 3.

Individual state fact sheets from Supporting Families are available in the DDSN supplemental notebook, Tab 3.

ThinkWork! Project

Holistic view of overall performance based on ID/DD, VR, and Education data.

Research Questions:

- What is the relationship between state employment system characteristics and employment outcomes ?
- How do specific Employment First efforts intersect?

State Employment Leadership Network

Reference documents are available
in the DDSN supplemental notebook, Tab 3

Key findings: composite indicator

	Rank	Overall CI Score	IDD Score	VR Score	Education Score
MD	1	47.38	21.60	15.22	10.56
NH	2	47.26	22.76	9.63	14.86
VT	3	46.88	22.76	13.75	10.37
OR	4	44.77	21.60	12.81	10.35
WA	5	44.26	22.84	10.87	10.56
IA	6	42.48	15.42	13.78	13.28
OK	7	41.98	21.67	12.79	7.52
SD	8	40.51	14.33	14.72	11.46
CO	9	39.78	14.47	13.92	11.39
DE	10	39.60	19.20	14.32	6.08

State Employment Leadership Network

Reference documents are available in the DDSN supplemental notebook, Tab 3

ThinkWork!

Top Performers Across Systems and States

Top 10 states based on CI Scores (ranked descending order)	Top IDD System Performers	Top VR System Performers	Top Education System Performers
• **Maryland**	• **Maryland**	• **Maryland**	• **New Hampshire**
• **New Hampshire**	• **New Hampshire**	• **South Dakota**	• Iowa
• Vermont	• Vermont	• **Colorado**	• **South Dakota**
• Oregon	• Oregon	• Delaware	• **Colorado**
• Washington	• Washington		
• Iowa	• Oklahoma		
• Oklahoma			
• **South Dakota**			
• **Colorado**			
• Delaware			

State Employment Leadership Network

Reference documents are available
in the DDSN supplemental notebook, Tab 3

ThinkWork!

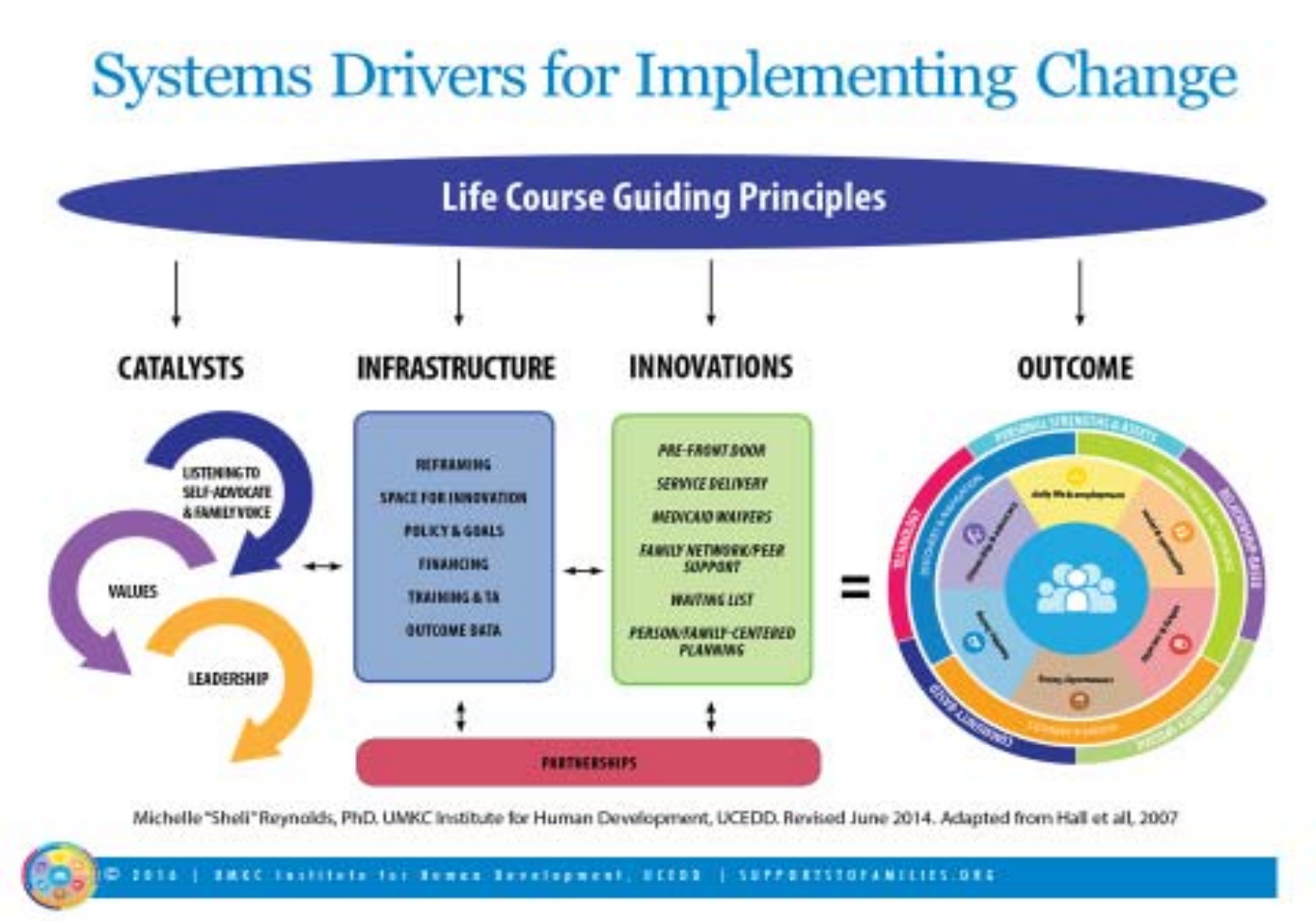
Supporting Families

National Community of Practices for Supporting Families of Individuals of ID/DD Across the Lifespan.

- Participating states have changed the front door into the system, improved cultural considerations in supporting families, guided and influenced policymakers and helped shape waivers and other Medicaid authorities to focus on supporting families and individuals throughout the lifespan.

Fact sheets on the states participating are available in the DDSN supplemental notebook, Tab 3.

Supporting Families



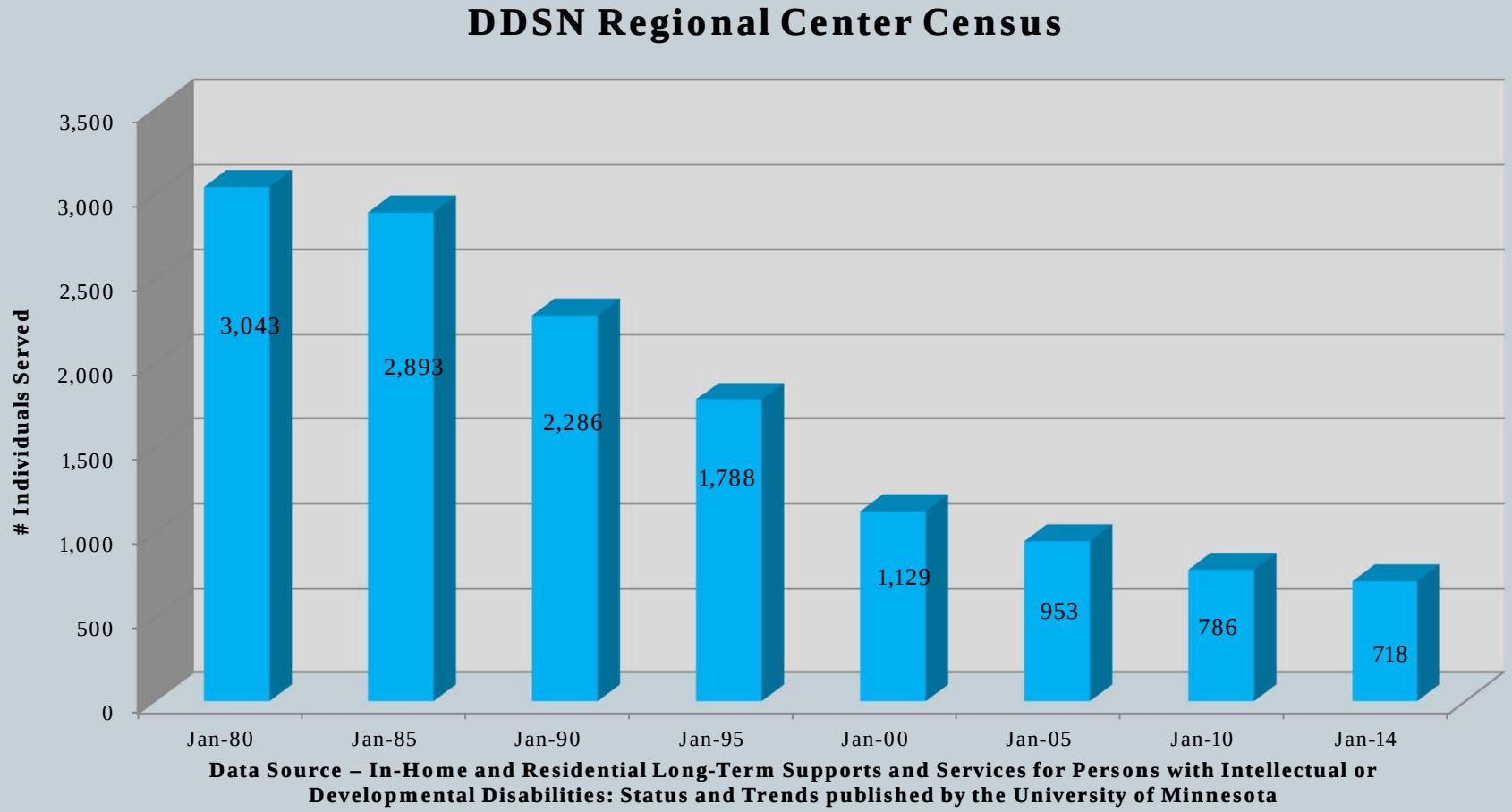
Links to the full reports referenced are available in the DDSN supplemental notebook, Tab 3.

DDSN Operated Regional Centers

Regional Center History

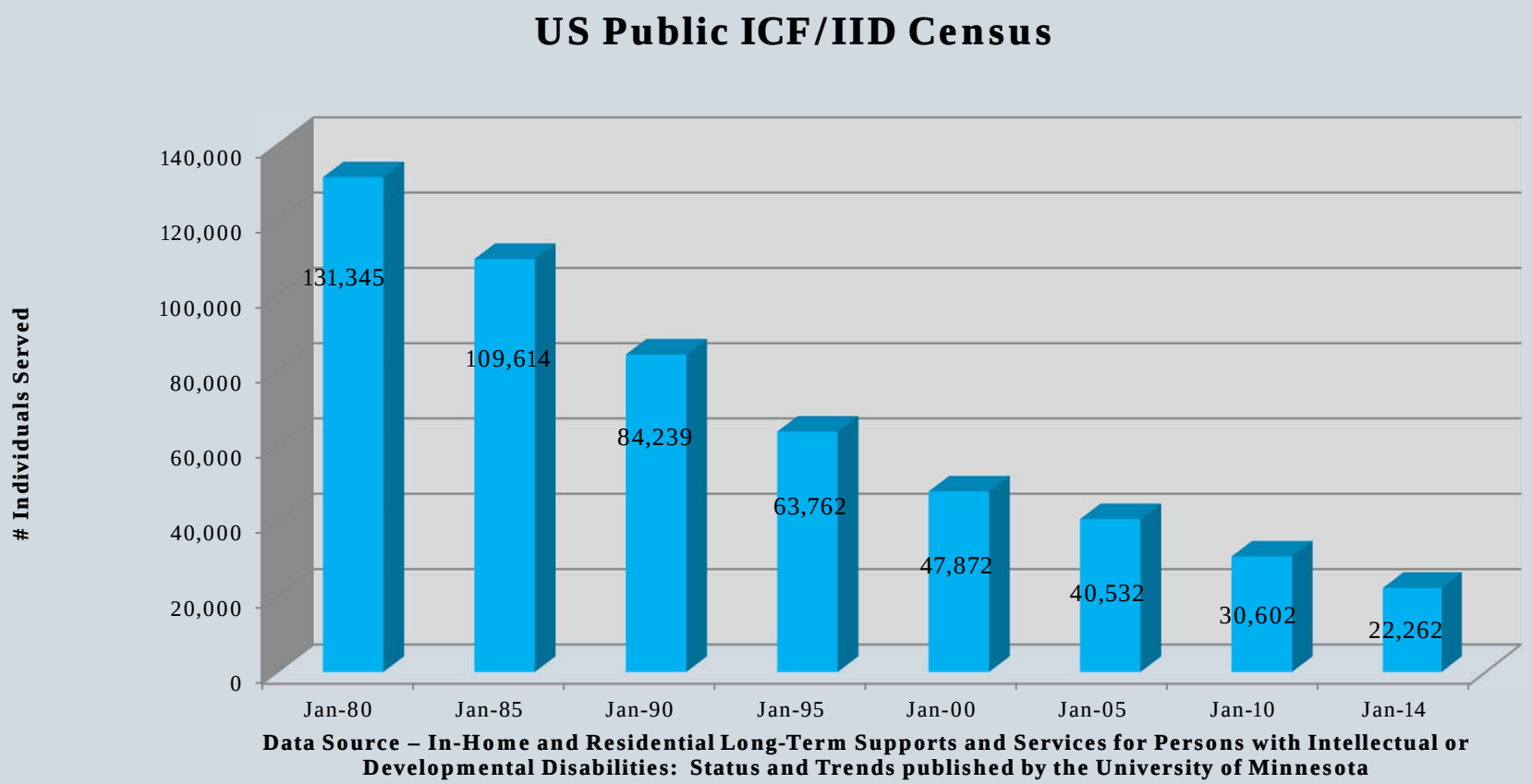
- Before 1980, regional centers used to be the only significant service available to South Carolinians with intellectual disabilities; this was typical of disability services available in other states.
- In 1980 there were 3,043 individuals served in DDSN regional centers.
- In keeping with national best practice, family preference and disability law, community services have become the primary service offered to South Carolinians with disabilities while the number of persons served in the regional centers has significantly declined.

Regional Center History



Links to the full reports referenced are available in the DDSN supplemental notebook, Tab 3.

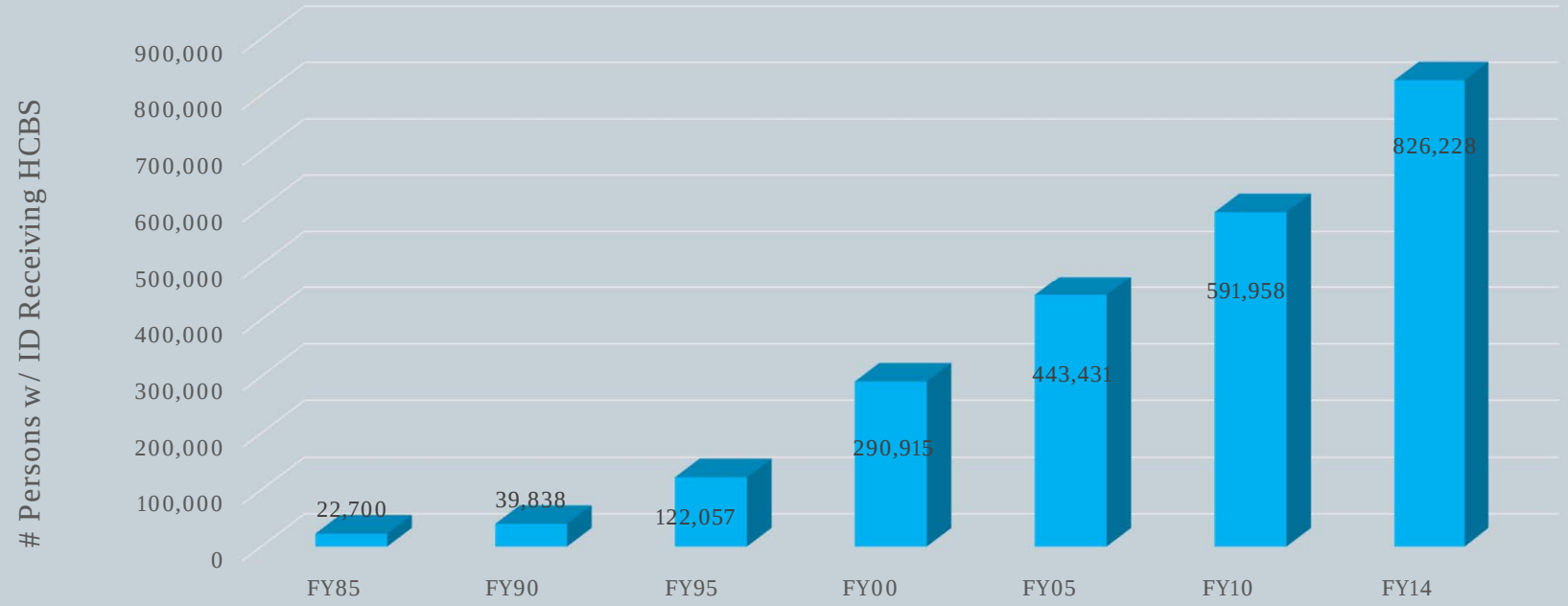
Regional Center History



Links to the full reports referenced are available in the DDSN supplemental notebook, Tab 3.

Regional Center History

Community Services for Persons w/ ID in US



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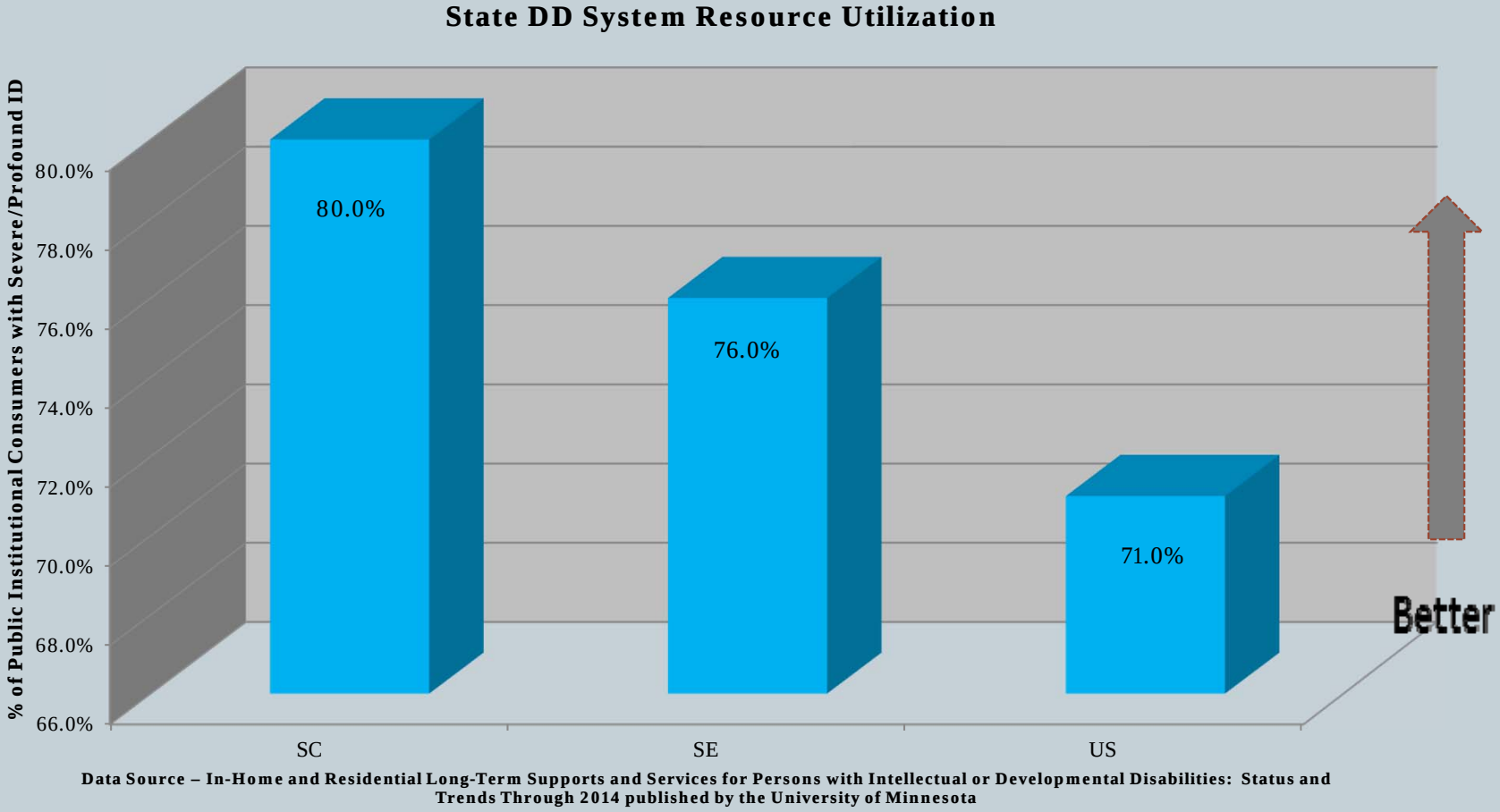
Regional Center History



Links to the full reports referenced are available in the DDSN supplemental notebook, Tab 3.

Regional Center Role

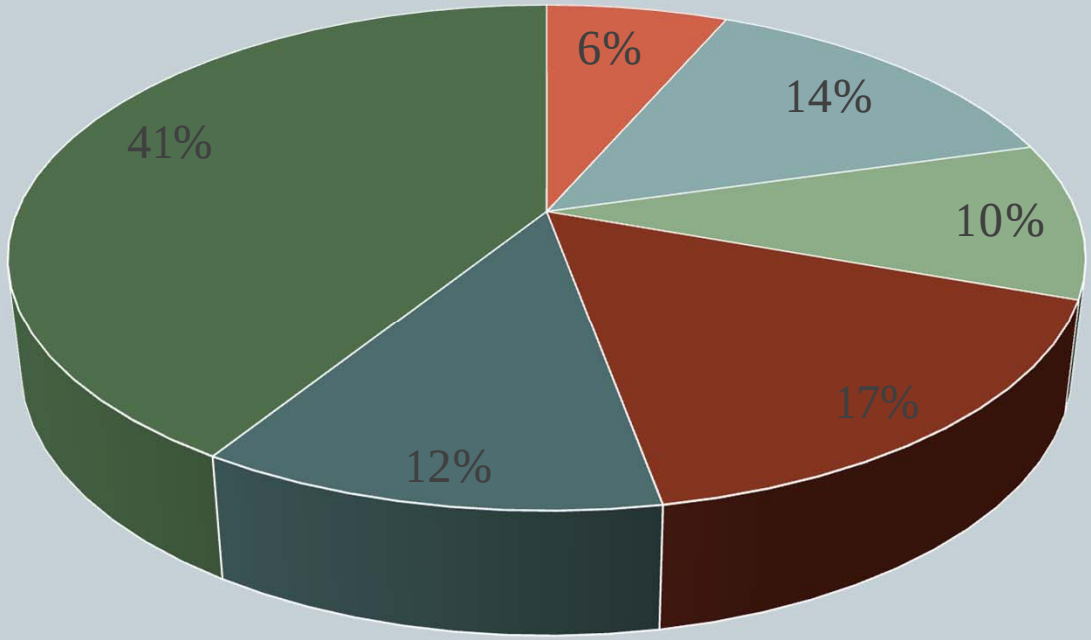
- DDSN currently operates five regional centers.
- Regional centers are geographically distributed around the state – Coastal Center in Ladson, Midlands Center in Columbia, Pee Dee Center in Florence, Saleeby Center in Hartsville and Whitten Center in Clinton.
- Regional centers provide 24 hour per day/365 day per year medical, therapy, psychological, recreational and personal care services.

Regional Center Role

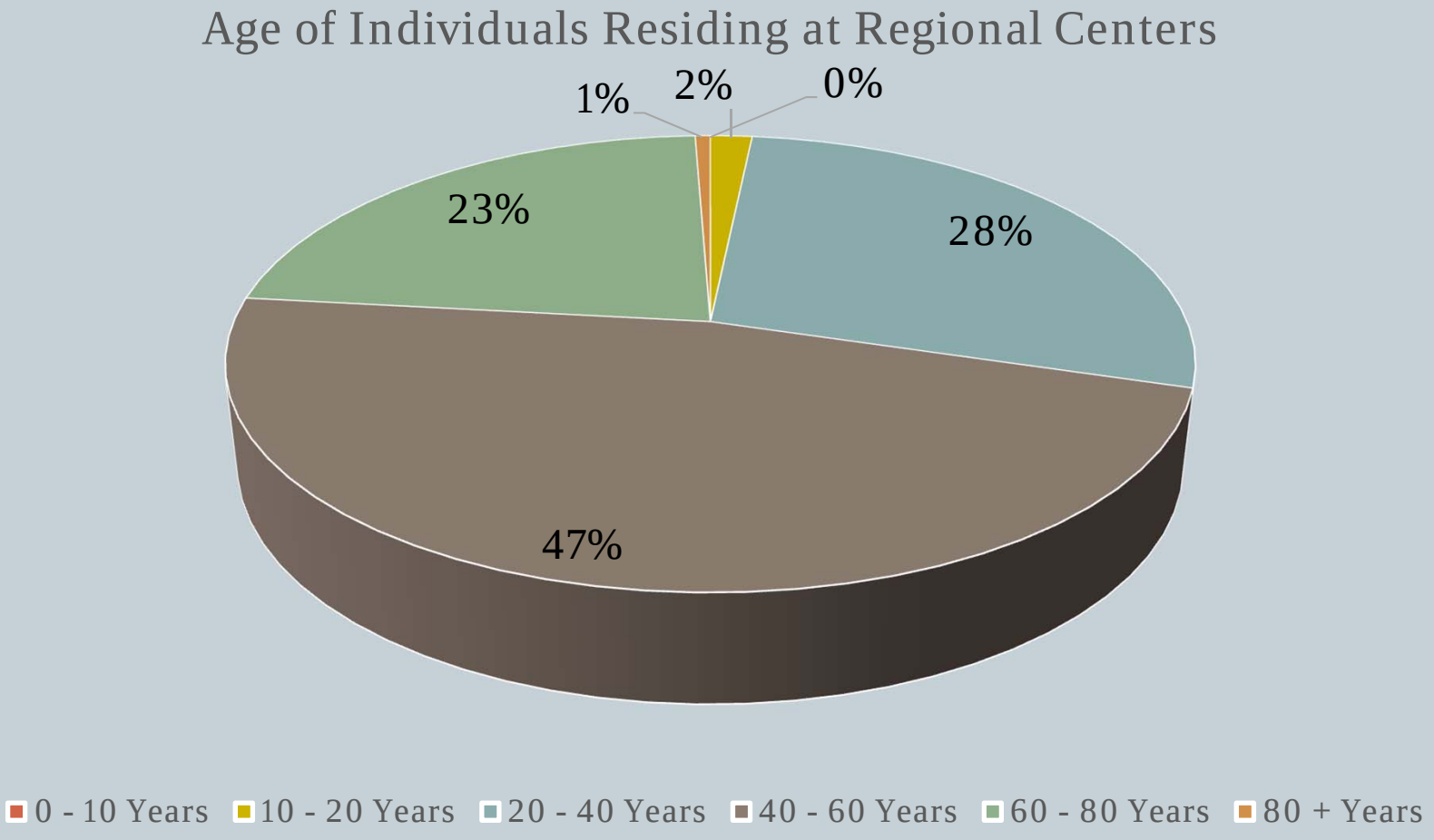
- The regional centers have always served as the safety net for the DDSN system.
- Typically individuals with the most complex medical or behavioral needs are supported at the regional centers; assuring that the most expensive and comprehensive services are offered to those with the most complicated needs.
- A small number of the individuals judicially admitted to DDSN after being found not competent to stand trial for criminal charges are served at the regional centers.

Regional Centers

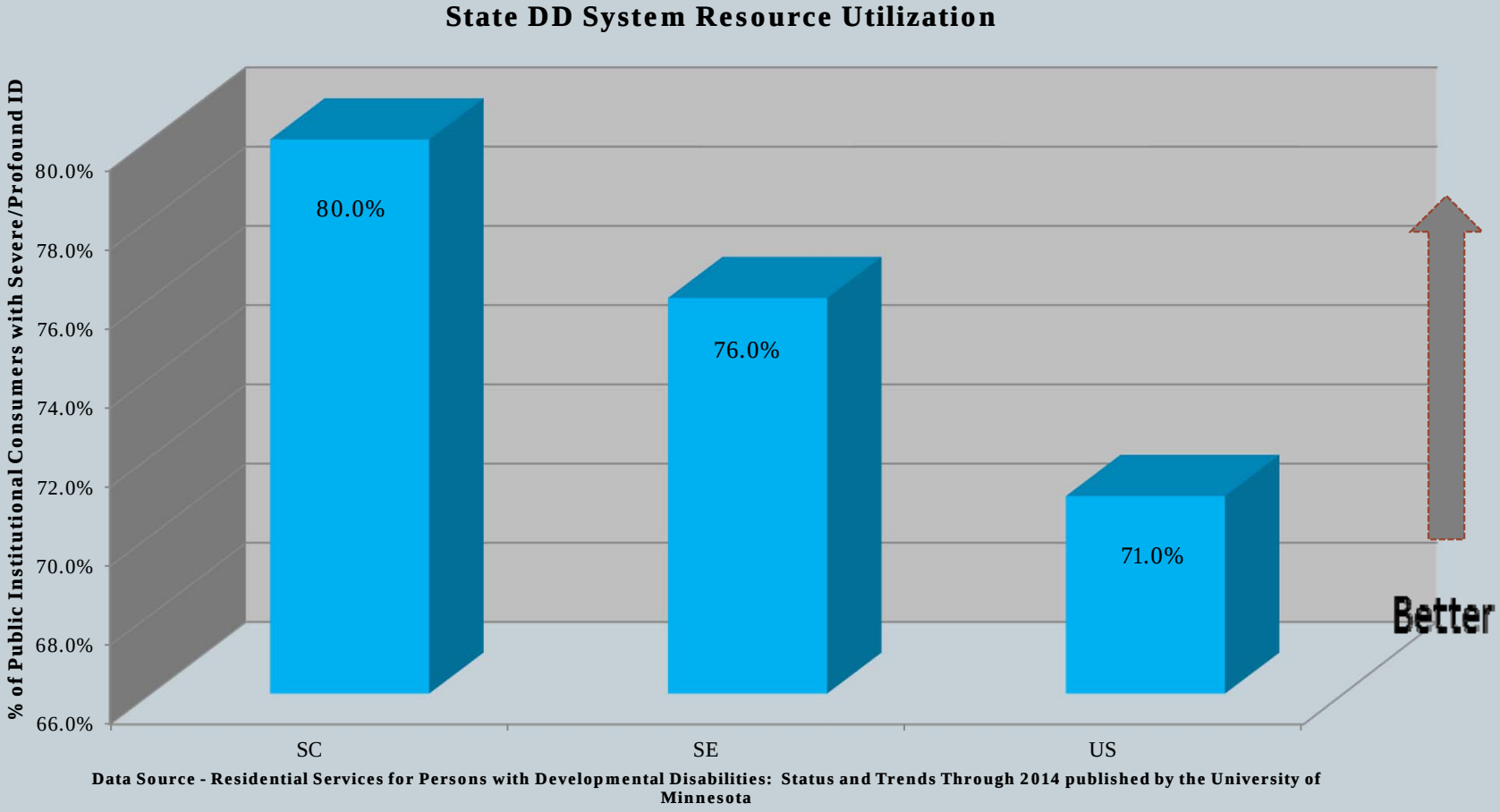
Length of Stay for Individuals Residing at Regional Centers



Regional Centers



Regional Center Role



Links to the full reports referenced are available in the DDSN supplemental notebook, Tab 3.

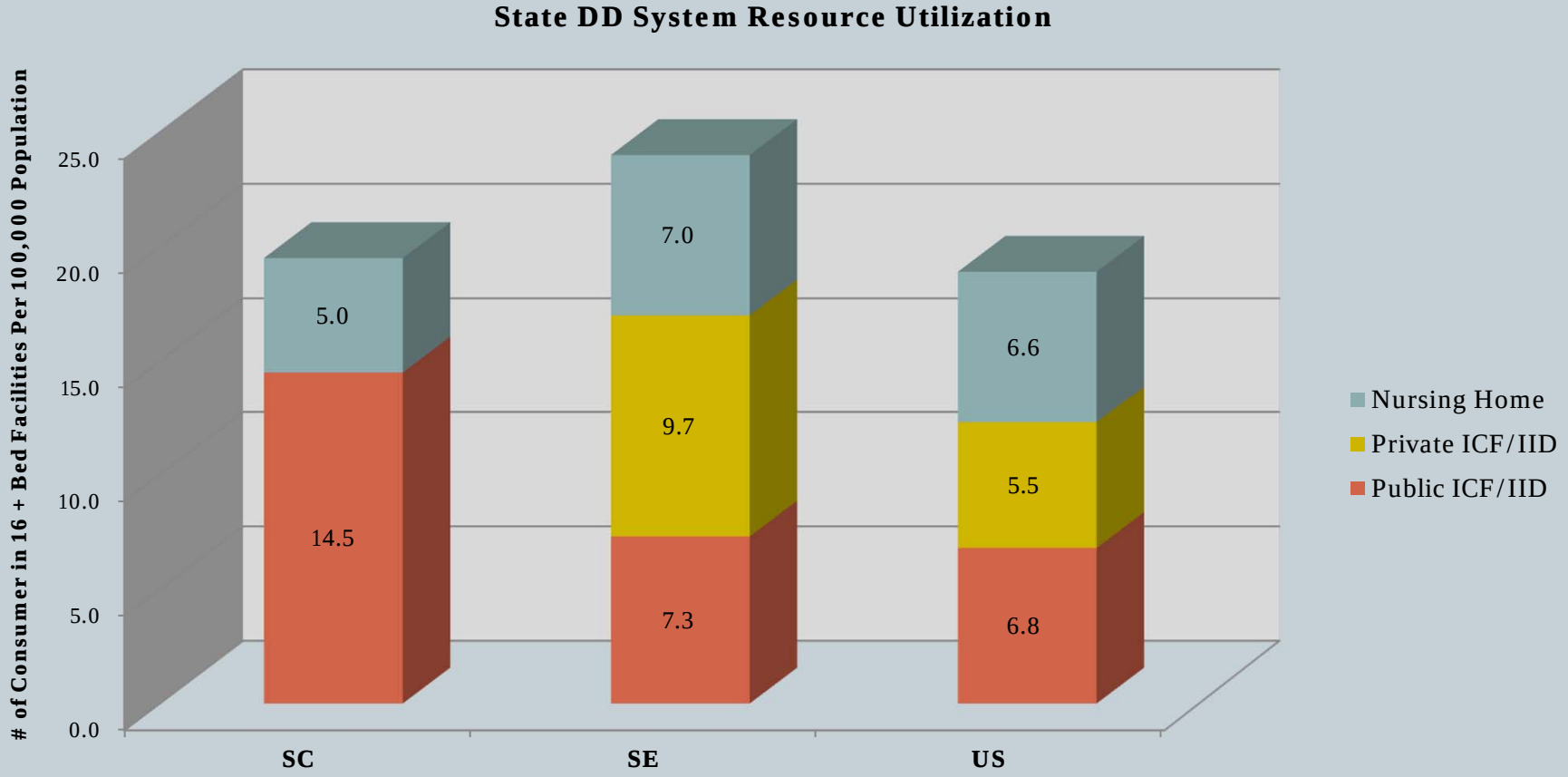
Regional Center Role

- Regional centers also provide respite for families with a family member with complex medical or behavioral needs residing in the family home.
- Last fiscal year, the regional centers provided 52 episodes of respite assisting both families and community providers.

Regional Center Role

- Families of individuals who reside at the regional centers are very supportive of the regional centers.
- As a result of family advocacy, in 2000 a South Carolina Code Ann. § 44-20-365 (Supp. 2016) was passed which required the General Assembly to approve the closure of any regional center.
- Due to DDSN's minimal of use of nursing homes, large private residential facilities and responsiveness to family preference, South Carolina serves more individuals in regional centers (public ICF/IID) than other states.

Regional Center Role



Data Source – In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends through 2014 published by the University of Minnesota

Links to the full reports referenced are available in the DDSN supplemental notebook, Tab 3.

Regional Center Resources

- The regional centers receive an annual budget from DDSN.
  - FY2017/2018 Budget is $94 million
- Regional centers are expected to operate within their budget, but DDSN works with the regional centers to assure funding is sufficient to protect consumer health and safety.

Regional Center Resources

- The regional centers employ 1701 staff.
- 68 % of these staff are paraprofessional direct support staff.
- The regional centers also employ a diverse work force to provide medical care, prepare food, maintain the physical plant.

Regional Center Resources

- As consumers chose to move from the regional center to the community, their funding follows them; as it does for consumers moving in between community providers.
- This funding portability is referred to as Money Follows the Individual (MFI).
- DDSN implemented this practice in 1992; the federal government encouraged states to adopt similar practices in 2000.
- Only a portion of the funding follows the consumer when they move from the regional center to the community.

Regional Center Resources

- The regional centers have a dedicated source of revenue for capital improvements unlike similar facilities in other states.
- This has allowed DDSN to annually invest approximately $1.3 million in necessary renovations to allow regional centers to offer a safe and comfortable living environment.
- Over the past five years, DDSN has expended approximately $6.6 million to allow the regional centers to replace HVAC systems, replace roofs, modify bathrooms to be ADA compliant, repair generators, upgrade kitchens and other essential capital projects.
- Many other states must seek capital funding from state legislatures which results in unstable and inconsistent funding.

National Influences - Olmstead

- US Supreme Court issued the landmark "Olmstead" ruling in 1999.
- Case involved two women with cognitive and psychiatric disabilities living in a Georgia psychiatric hospital who wanted to receive services in the community.
- The Olmstead ruling was based upon the US Supreme Court's interpretation of the rights granted under the Americans with Disabilities Act which was enacted in 1990.

National Influences - Olmstead

- Olmstead ruling required states to support persons with disabilities in small community settings rather than larger facility settings when:
  - The individual/guardian chooses to be served in community.
  - Treatment professionals believe that community services can safely and effective meet person's needs.
  - The provision of services in the community does not require a fundamental alteration of the existing service system.
- In general the Olmstead ruling promotes consumer choice in service setting and serving consumers in the least restrictive and most community integrated setting which can effectively meet their needs.

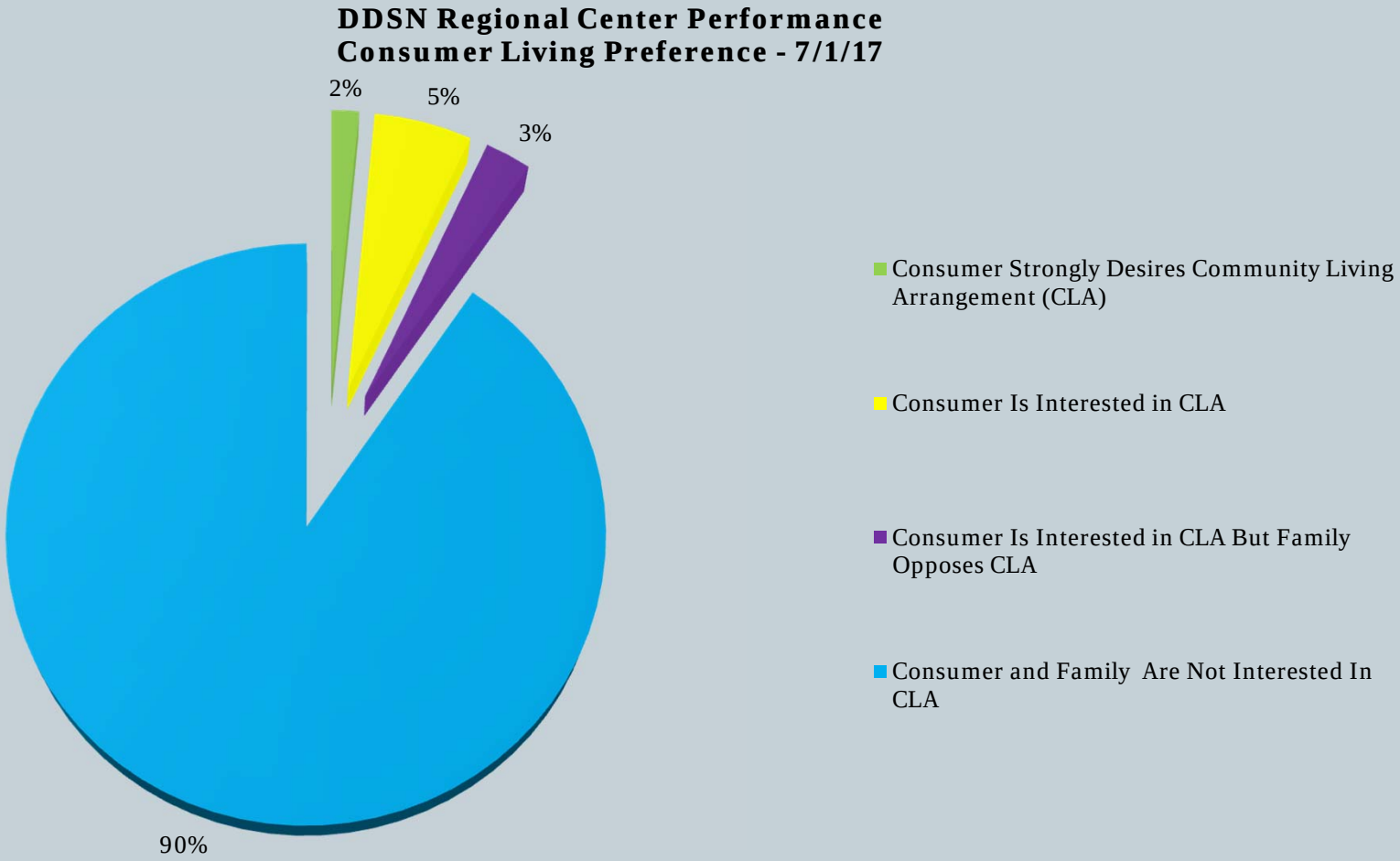
National Influences - Olmstead

- DDSN has taken many steps which assist in maintaining compliance with the Olmstead ruling.
- DDSN established wage parity between Regional Center and community provider direct care staff.
  - The absence of parity can inhibit consumers moving from Regional Centers to community settings when the consumer desires to move.

National Influences - Olmstead

- Implemented systematic process to assess living preference of all individuals served in Regional Centers.
- Regularly notify community providers of consumers living at Regional Centers who want to be served in community.
- Increased the capacity of the private residential service providers which offers additional consumer choice especially for consumers living at the Regional Centers who desire to move to the community.

Regional Center Positive Outcomes



National Influences - Olmstead

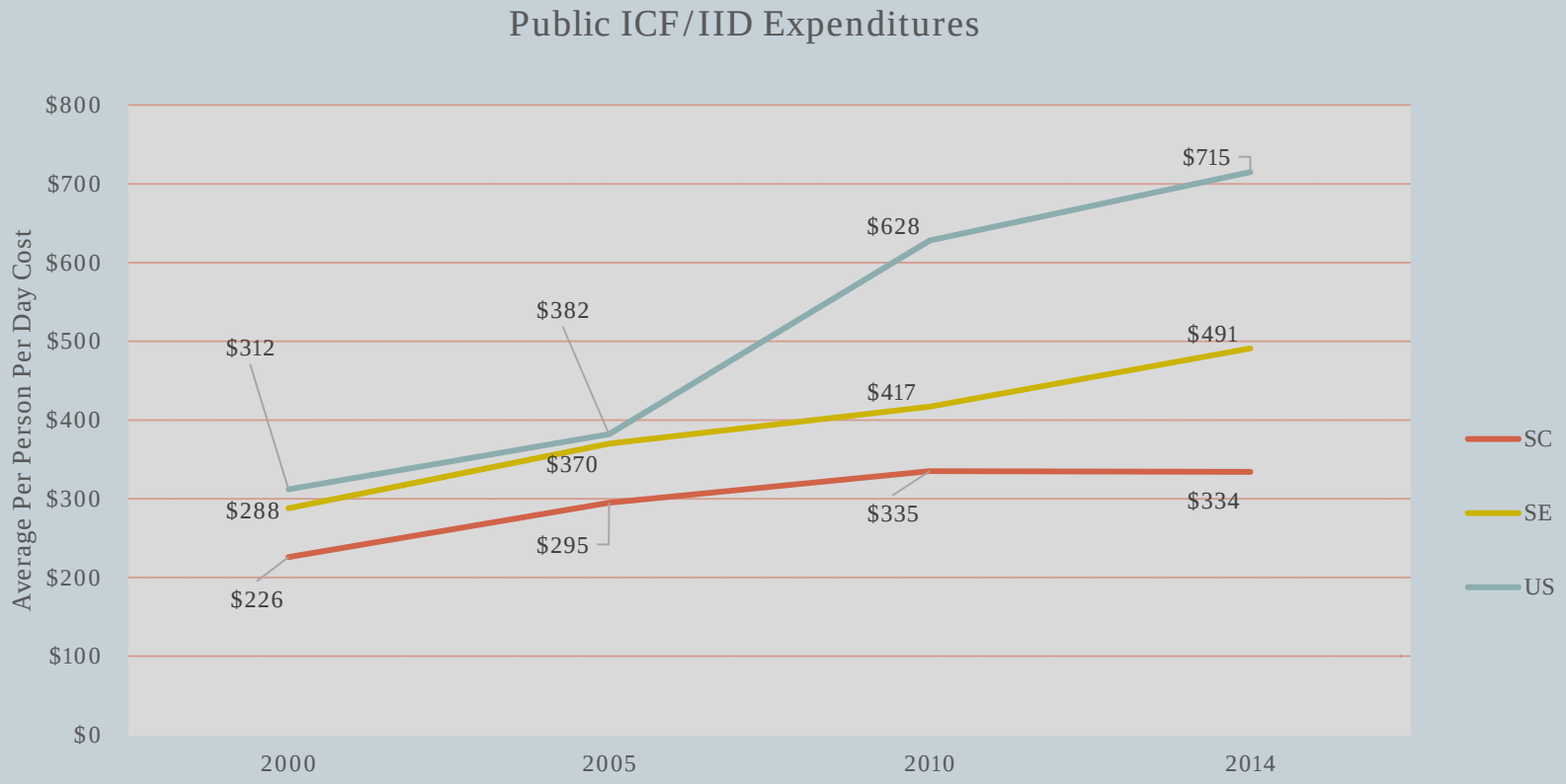
- Developed more systematic and thorough transition process to assure consumers' needs are met when moving from Regional Centers to community residential setting.

- Implemented more vigorous Regional Center admissions review process to assure only those individuals requiring the intensive services offered at Regional Center are admitted.

National Influences - Olmstead

- Prior to late 2009, the US Department of Justice (DOJ) had never filed any legal action strictly based upon the Olmstead case/ADA.
- Since November 2009 the DOJ has filed 10 Olmstead/ADA Title II legal actions and 10 Olmstead/ADA Amicus/Statement of Interest briefs.
- Two states have been forced to close nearly all of their public ICFs/IID as a result of DOJ ADA actions (Georgia and Virginia) resulting in significant cost increases.

National Influences - Olmstead



Data Source – In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends published by the University of Minnesota

Links to the full reports referenced are available in the DDSN supplemental notebook, Tab 3.

Regional Center Challenges

- Olmstead/ADA compliance
  - While DDSN has done a good job of assuring a consistent reduction in the number of individuals served at its regional centers, we still rely more heavily on regional centers than most states.
  - The needs of the individuals who live at the regional centers but want to move to the community are becoming more significant creating challenges for community service providers to successfully support them.

Regional Center Challenges

- Crisis support for communities
  - As the size and resources of the regional centers decline, it is becoming more difficult for the regional centers to provide the immediate support often required for individuals in crisis who are living in the community with family or community providers that they have provided in the past.
  - While there have been efforts to increase the supply of behavior support providers, there continues to be an inadequate number to serve those individuals with complex behavioral needs in the community.

Regional Center Challenges

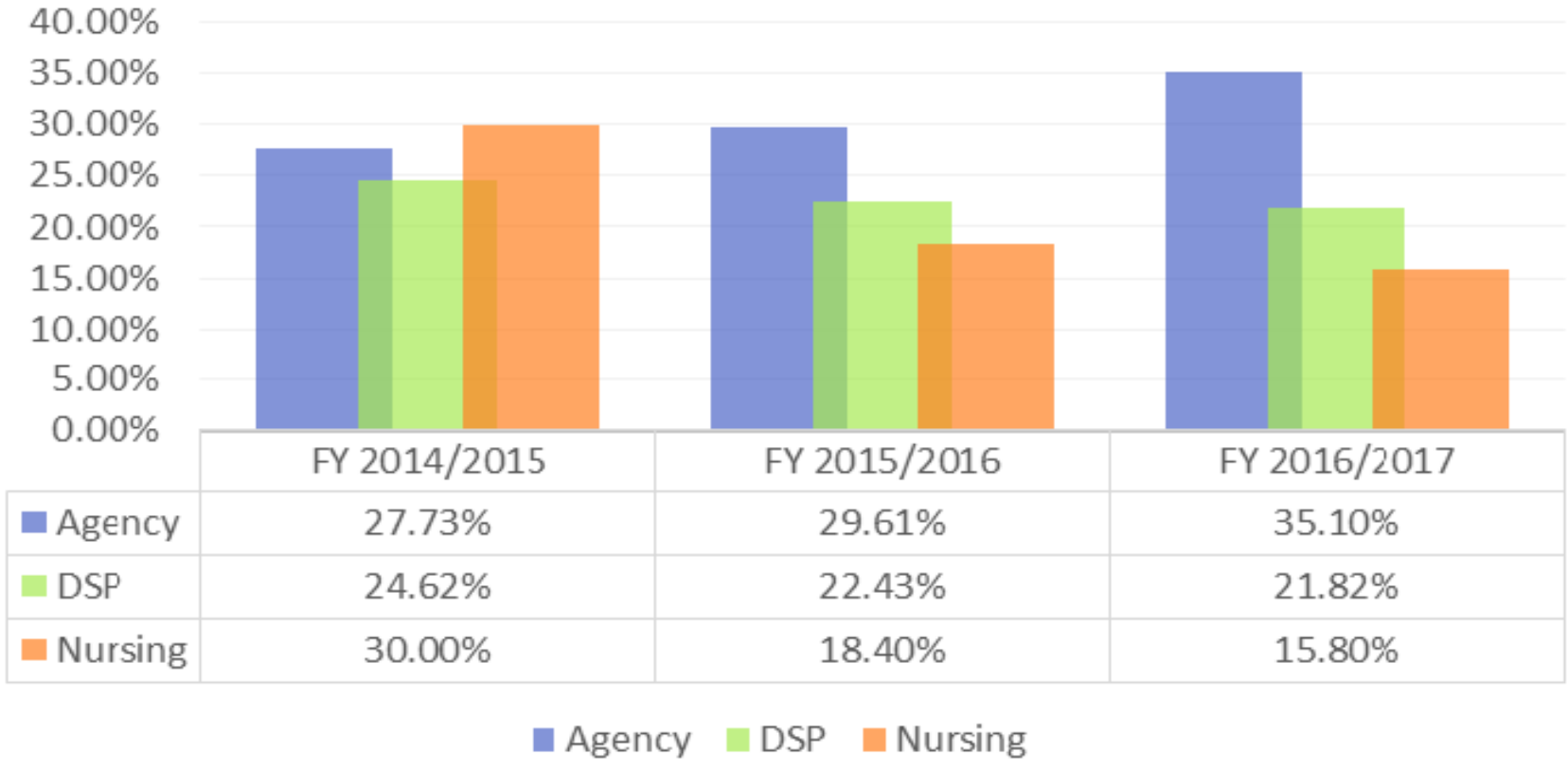
- Crisis support for communities
  - Though DDSN has enhanced payment rates for community providers to serve individuals with complex needs who want to move from the regional centers, this effort needs to be expanded to assure adequate supply of quality services.
  - DDSN continues to see a reduction in the number of providers willing to offer services to individuals with significant behavioral challenges.

Regional Center Challenges

- Direct support staff ratios:
  - Direct support staff are the backbone of services provided at our regional centers.
  - While regional center direct support staff ratios have improved, the increase has not been sufficient to maintain direct support staff ratios at a level comparable to the national average.

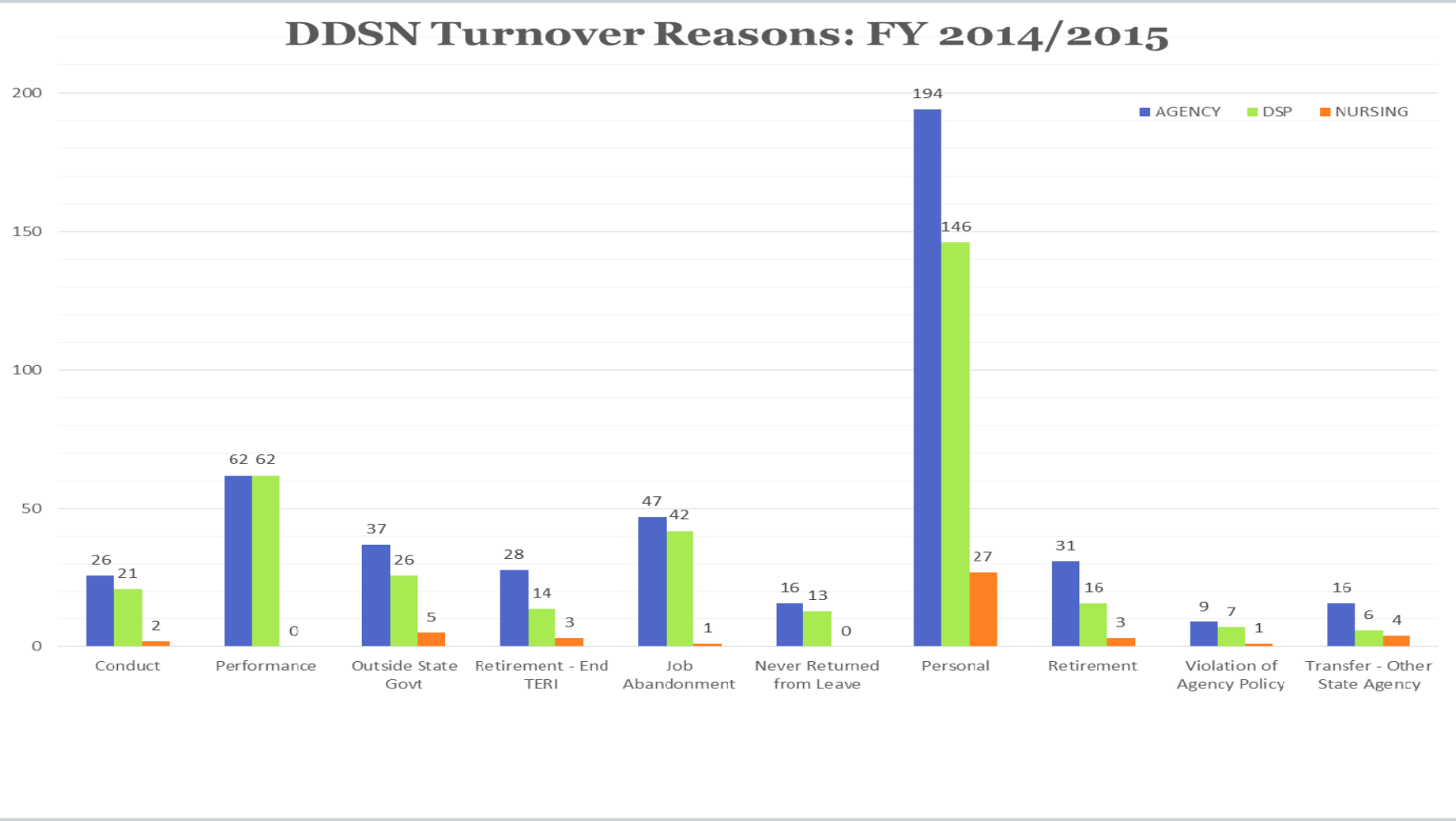
Turn Over Rates

DDSN Turn Over Rates

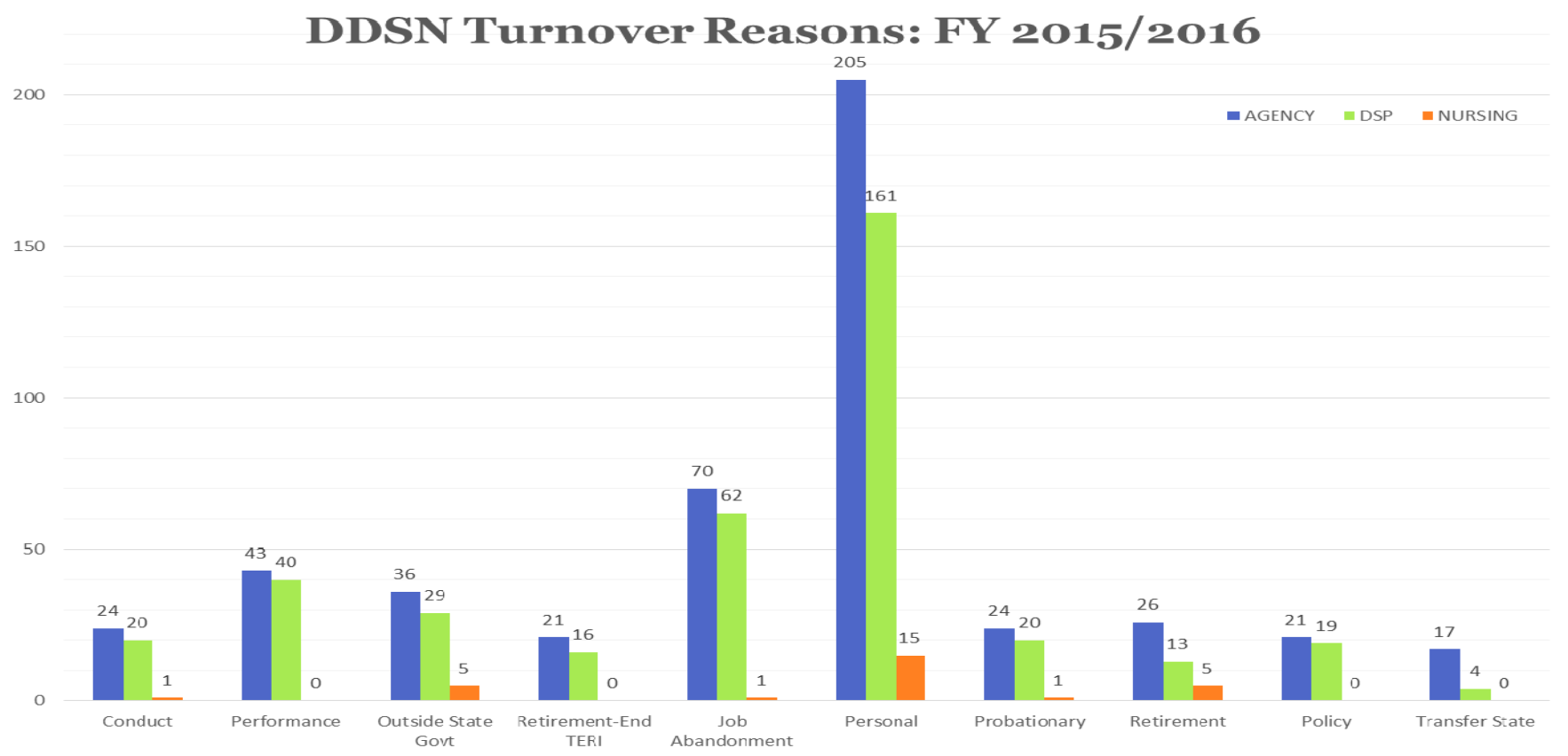


	FY 2014/2015	FY 2015/2016	FY 2016/2017
Agency	27.73%	29.61%	35.10%
DSP	24.62%	22.43%	21.82%
Nursing	30.00%	18.40%	15.80%

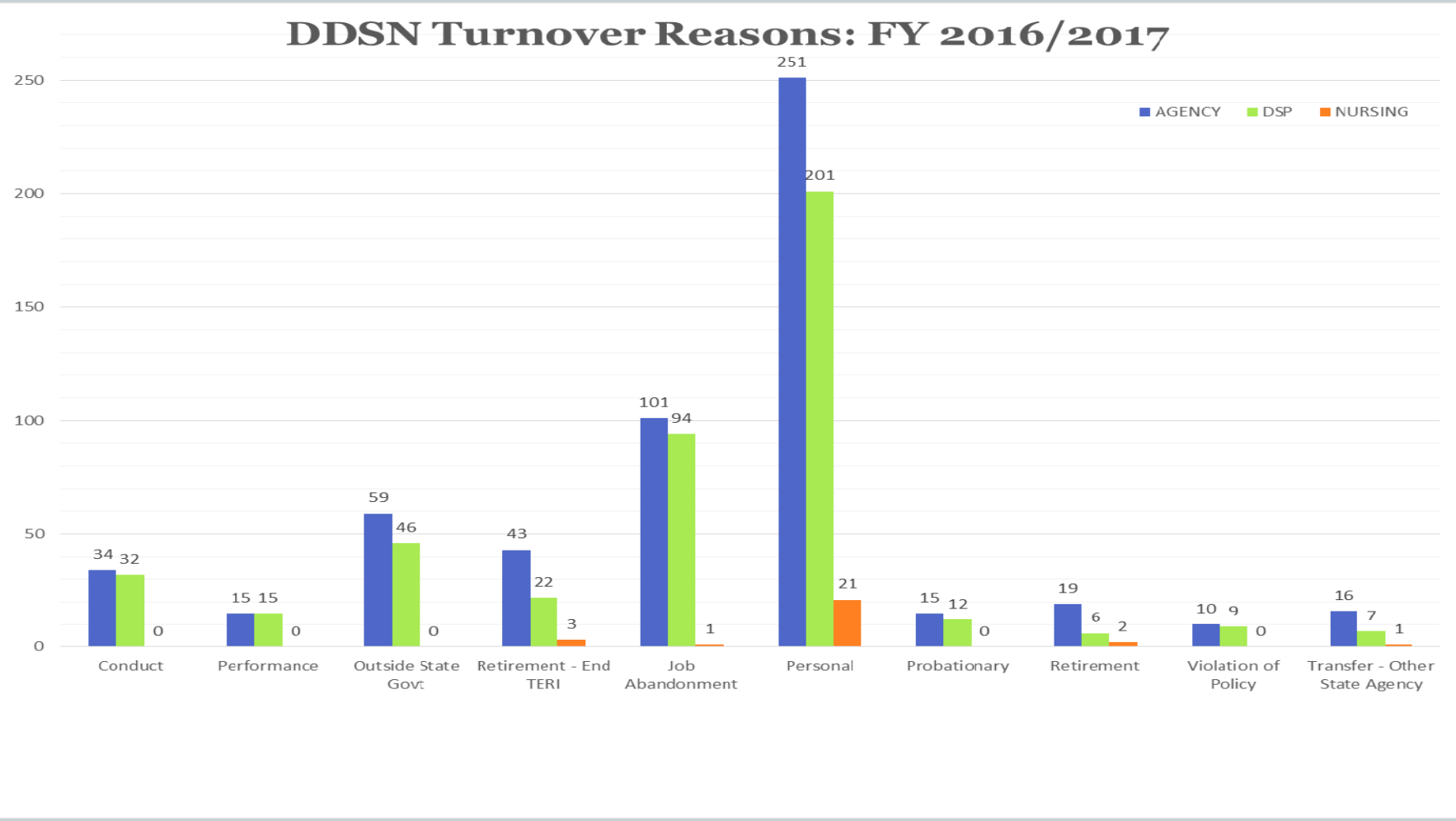
DDSN Turnover Reasons: FY 2014/2015



DDSN Turnover Reasons: FY 2015/2016



DDSN Turnover Reasons: FY 2016/2017



Provider Oversight

Abuse, Neglect, Exploitation Allegations and Resolution

South Carolina Abuse, Neglect, Exploitation (ANE) Allegation Resolution Process

- DDSN has no statutory authority to prevent providers from returning staff to work prior to completion of a criminal investigation.
- The authority DDSN exerts over providers related to the Abuse, Neglect, Exploitation allegations is held within the contractual relationship between providers and DDSN.

DDSN Contractual Relationship with Providers

- Provider contracts require that the provider comply with the terms of the Fixed Price Bid solicitation.
  - Assurance 6.4 of the solicitation requires: ”Case Management shall be provided in compliance with all of the terms, conditions, applicable policy directives and standards for the provision of Case Management services and with all future terms, conditions, standards, and updates that are established by The Agency. Case Management Standards and applicable policy directives can be found on The Agency’s website”
  - Furthermore, the DDSN Special Terms and Conditions of the solicitation requires that “The Contractor shall comply with all current DDSN standards, policies, procedures, directives, and requirements for services. Failure to comply with all DDSN standards, policies, procedures, directives, and requirements for services may be considered a breach of contract.”

Provider contract amounts available in the notebooks, pages 44 - 105 of 189.

DDSN Requirements for Reporting ANE Allegations

DDSN Directive 534-02-DD

Procedures for Preventing and Reporting Abuse, Neglect, or Exploitation of People Receiving Services from DDSN or a DSN Board or Contracted Service Provider

A full copy of Directive 534-02-DD is provided in the notebooks, pages 139 – 172 of 189.

A PowerPoint presentation for purposes of training DSN providers is provided in the notebooks, pages 173- 188 of 189.

DDSN Provider Oversight

Returning Staff to Work:

Criminal cases:

- If the provider has not received a written Case Status Report from the investigative agency (SLED or LLE), then a Request for Reinstatement must be submitted to DDSN and approved in advance of the employee's return to work.
- The provider may document any verbal findings on the Request for Reinstatement noting the name of the investigator providing the information and the date given.

DDSN Provider Oversight

Returning Staff to Work:

Criminal cases (continued):

- DDSN Provider staff are often told when an investigation has concluded, but it may take several days for the appropriate supervisor to review and officially close the case.
- If the provider has received written Case Status report from SLED or LLE indicating case closed as Unfounded or Unsubstantiated and completed Management Review, then the date the date staff will return to work may be indicated on the Management Review (or in an Addendum) and any applicable disciplinary actions or staff training noted.

Non-criminal Cases:

- The employee may return to work once the Administrative Review is completed to determine if there was any improper conduct or if there were any policy/ procedural violations.
- The date staff will return to work may be indicated on the Administrative Review (or in an Addendum) and any applicable disciplinary actions or staff training noted.

Waiting List By County

County	IDRD	CSW	Unduplicated
Abbeville	30	8	32
Aiken	334	169	364
Allendale	15	7	17
Anderson	336	168	357
Bamberg	28	21	34
Barnwell	27	16	33
Beaufort	122	60	132
Berkeley	201	122	246
Calhoun	27	18	30
Charleston	335	168	372
Cherokee	92	47	99
Chester	40	14	42
Chesterfield	57	33	64
Clarendon	45	26	49
Colleton	47	23	50
Darlington	82	47	90
Dillon	39	18	42
Dorchester	212	116	228
Edgefield	23	14	23
Fairfield	16	7	20
Florence	204	112	222
Georgetown	59	28	63
Greenville	955	539	1038
Greenwood	63	41	75
Hampton	13	8	15
Horry	345	196	375
Jasper	24	10	27
Kershaw	108	48	113
Lancaster	114	52	124
Laurens	77	39	87
Lee	18	15	24
Lexington	619	303	664
Marion	38	17	44
Marlboro	37	13	38
McCormick	13	8	13
Newberry	52	28	58
Oconee	190	94	194
Orangeburg	142	56	155
Pickens	190	99	200
Richland	890	378	939
Saluda	14	12	16
Spartanburg	496	239	534
Sumter	110	76	135
Union	38	20	42
Williamsburg	36	17	39
York	431	249	459
Total	7384	3799	8017

UCP United Cerebral Palsy

the case for Inclusion

2016

2016 REPORT

INTRODUCTION

At no other time in history than now, and in no other place in the world than America, does a person born with intellectual and developmental disabilities (ID/DD) have the best opportunity for a long, healthy, full and meaningful life.

That did not happen by accident.

It happened over decades as a direct result of advocacy and successful policy reforms at the federal and state level, as a result of the work of United Cerebral Palsy and our colleagues in the community.

It continues to be true due to three things: vigilance, cooperation, and progress.

Vigilance to protect the gains that have been achieved in the states and at the federal level with policy and funding to effectively support individuals with intellectual and developmental disabilities.

Progress to show the areas that need attention, reform and improvement to provide further opportunity and inclusion for all Americans with intellectual and developmental disabilities.

And, cooperation to provide this resource and others to advocates and partners throughout the country.

And so it is, that every year since 2006, United Cerebral Palsy (UCP) releases *The Case for Inclusion*, the preeminent annual ranking of how well state Medicaid programs serve Americans with intellectual and developmental disabilities (ID/DD) and their families.

While all states have room for improvement, some states do much better than others in demonstrating the needed political will and sound policies—as well as focused funding—necessary to achieve this ideal.

The Case for Inclusion ranks all 50 States and the District of Columbia (DC) not on their spending but on their outcomes for Americans with ID/DD.

The Case for Inclusion is a tool that gives us: glimpses at how well each individual state is performing overall; how each state matches up against other states regarding key data measures; the policies and practices of top performing states that may be considered as best practices; and, most importantly, the trends and trajectory of how states are—or are not—improving.

ABOUT UNITED CEREBRAL PALSY

UCP educates, advocates, and provides support services through an affiliate network to ensure a life without limits for people with a broad range of disabilities and their families. Together with nearly 70 affiliates, UCP has a mission to advance the independence, productivity and full citizenship of people with disabilities by supporting more than 176,000 children and adults every day—one person at a time, one family at a time. UCP works to enact real change—to revolutionize care, raise standards of living, and create opportunities—impacting the lives of millions living with disabilities. For more than 60 years, UCP has worked to ensure the inclusion of individuals with disabilities in every facet of society. Together, with parents and caregivers, UCP will continue to push for the social, legal, and technological changes that increase accessibility and independence, allowing people with disabilities to dream their own dreams, for the next 60 years, and beyond.

THE CASE FOR ACTION

The tireless work of advocates locking arms with principled elected officials achieved the unprecedented progress of moving thousands of Americans from isolation in large state institutions to living in the community in home-like settings, and to having a life full of richness through participation in work, friendships, and all aspects of the community.

What the Report Does

The annual *Case for Inclusion* report provides the framework and facts for continued advocacy, for the protection of the accomplishments achieved, and for providing clear direction to those areas that need further improvement.

Case does this by: holistically ranking the states; showing the sub-rankings of each state in 5 key outcome areas (to showcase the best in class, and those states needing improvement); and, by highlighting key policy reforms or narrative case studies to point the way to further state-level progress.

Why *Case* Matters

It is hard to find facts about how Medicaid services impact the lives of Americas with ID/DD. *Case* pulls several forms of data together in one place, provides clear links and references to more extensive reports, and combines multiple measures to paint a more complete picture of what the state is: 1) doing, 2) not doing, 3) doing well, or 4) not doing well.

It is important because data matters, and elected officials respond to rankings and comparisons. This gets their attention and focuses them on what outcomes matter the most. But, also, this data is not just numbers. This data represents real people, with real needs, and they have real stories. *Case* tells that story in a way that policymakers and government agencies can use.

How You Can Use It

Facts matter. Context matters. Comparisons matter. *Case for Inclusion* gives all three to advocates so that they can be fact-based in their work and not allow the defenders of the status quo to pretend that a better way is not possible. This is your tool to facilitate the conversation on what is working, and where more resources are needed. There are always states doing a better job. *Case* shows which states are outstanding, and showcases that improvement is possible and easily attainable with focused attention, the necessary resources, and sound public policy.

Getting Results in Your State with the *Case for Inclusion* Report

Advocates and families have tremendous power to be a force for good in their state or to resist a rolling back of progress that has been achieved. Here are three ways to use this report in your advocacy work in your state:

- **Waiting list (s)** - while so much progress has been made to better serve individuals in the community, for 208,000 individuals nationally, resitential services are still out of reach because of a lack of funding and prioritization at the state level. UCP suggests that:
  - First, policymakers pass transparency legislation to ensure an accurate and transparent waiting list is maintained.
  - Second, that any remaining Medicaid funds at the end of the fiscal year, or from departmental budget saving initiatives, be directed to fund those highest priorirty indiviuals on the waiting list (often adults with aging parent caregivers).
  - Third, that annual legislation or budget amendments are considered to further reduce the waiting list.
- **Competitive employment** - Living in the commmunity is vital, but work is also key to a full and meaningful life. While 46 states have Employment First policies, nationally there are states falling behind when it comes to the proportion of individuals with ID/DD actually in competitive employment. In fact, there are fewer people in competitive employment than a decade ago: despite 325,000 more people being served by HCBS waivers. While Washington State showcased the initial Employment First policy to get almost all (86%) individuals with ID/DD served working, it also showed that it is not just about a policy change but also a priority. Advocates should push for specific strategies and reporting to actually achieve increasted competitive employment. A recent UCP case study highlights such approaches.
- **State Institutions** - During the Great Recession and after, tight state budgets forced policymakers to take a hard look at closing expensive (and isolating) state institutions. While the economy has improved, Medicaid budgets are still tight. Advocates in the 36 states with at least one state institution should leverage this fiscal environment and continue to push to close these facilities, transition individuals to the community, and to use any savings to reduce their state's waiting list.

How It Makes a Difference

UCP has seen numerous states adopt policy reforms directly related to measures that we track, score and rank states on—from participation in the quality assurance surveys of the National Core Indicators, to promoting work and competitive employment with Employment First policies, to reductions in waiting lists and improved waiting list tracking in numerous states.

The combination of data, advocacy and proven reforms have a huge impact on real Americans. These changes are literally life changing for individuals with ID/DD living in those states.

FOUR KEY ASPECTS OF A HIGH FUNCTIONING MEDICAID PROGRAM FOR AMERICANS WITH ID/DD

The University of Minnesota's Research and Training Center on Community Living concisely identifies the four key aspects of a high functioning and effective Medicaid program, which have also been articulated in a number of legislative, administrative and judicial statements describing national policy.[1] *The Case for Inclusion*'s five major outcome areas align, as indicated, with the following four-part holistic approach:

1. **Promoting Independence:**
   People with disabilities will live in and participate in their communities.
2. **Promoting Productivity:**
   People with disabilities will have satisfying lives and valued social roles.
3. **Keeping Families Together and Reaching Those In Need:**
   People with disabilities will have sufficient access to needed support, and control over that support so that the assistance they receive contributes to lifestyles they desire.
4. **Tracking Health, Safety, and Quality of Life:**
   People will be safe and healthy in the environments in which they live.

One note on the data. The rankings in this report are a snapshot in time using 30 different data measures across all five major categories.

Most data is from 2014, which is the most recent data available from credible, national sources. All data is sourced directly from the states to the federal government, and in response to public surveys. Notably, there are weaknesses in some of the data sources. UCP references data from credible recognized sources, but much of the data is self-reported to those sources by the state themselves.

UCP has experienced inherent definitional and numerical disparities in some data reported. Where UCP discovers glaring anomalies in the data, our protocol is to follow up with the data sources and provide them an opportunity to correct the data. Nonetheless, UCP expects that there will be some inherent inconsistencies in data that is self-reported by all fifty states and the District of Columbia.

1. The University of Minnesota Research and Training Center on Community Living. "Medicaid Home and Community Based Services for Persons with Intellectual and Developmental Disabilities – Interim Report." September 26, 2005. Page 3.

CFI DATA MEASURES

Category	Measure		2007-2013		2016	
Promoting Independence	Community-Based	% of Recipients with ID/DD on HCBS	9	50	9	50
		% of ID/DD Expenditures on HCBS	7		7	
		% of ID/DD Expenditures on Non-ICF-MR	8		8	
	Residential Services in the Community (includes all types)	1-3 Residents - %	13		13	
		1-6 Residents -%	11		11	
		16+ Residents % (smaller %, higher rank)	-4		-4	
		% in Large State Facilities	-3		-3	
	Waivers Promoting Self-Determination		2			
	NCI - % Self-Directed				2	
Tracking Health, Safety & Quality of Life	Quality Assurance - NCI Participation		6	12	0	14
	NCI - Recent Dental Visit				2.8	
	NCI - Lonely Less than Half the Time				2.8	
	NCI - Not Scared in Own Home				2.8	
	NCI - Inclusion (sum of 4 measures)				2.8	
	NCI - Relationships Other than Staff and Family				2.8	
	Abuse		6			
Keeping Families Together	Family Support per 100k		6	12	3	8
	% in a Family Home		6		3	
	NCI - Child/Family Survey Participation				2	
Promoting Productivity	Has Medicaid Buy-In Program		2	10	2	12
	Competitive Employment - %		6.5		4.0	
	Voc Rehab - per 100k		1.5			
	Voc Rehab - Rehab Rate (finding a job)				2	
	Voc Rehab - Number of Hours Worked				2	
	Voc Rehab - Retain Job for One Year				2	
Reaching Those in Need	Waiting List - Average % Growth for Residential and HCBS		9	16	9	16
	Individuals with ID/DD Served per 100k of Population		3		2	
	Ratio of Prevalence to Individuals served		4		2	
	Uses Federal Functional Definition for Eligibility or Broader				3	
				100		100

Eliminated - regularly updated data no longer consistently available

New - new measure added in 2014

SIGNIFICANT TAKEAWAYS FROM THE 2016 RANKINGS

PROMOTING INDEPENDENCE

1 **All states still have room for improvement, but some states have consistently remained at the bottom of the ranking since 2007,** including Arkansas (#49), Illinois (#47), Mississippi (#51) and Texas (#50) primarily due to the small portion of people and resources dedicated to those in small or home-like settings in these four states.

2 **32 states, same as last year, meet the 80/80 Home and Community Standard,** which means that at least 80 percent of all individuals with ID/DD are served in the community and 80 percent of all resources spent on those with ID/DD are for home (less than 7 residents per setting) and community support. Those that do not meet the 80/80 standard are: Arkansas, Delaware, Florida, Illinois, Indiana, Iowa, Kentucky, Louisiana, Mississippi, New Jersey, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Texas, Utah and Virginia. Connecticut is very close (with 79% spent on HCBS).

3 **As of 2014, 15 states report having no state institutions to seclude those with ID/DD,** including: Alabama, Alaska, Colorado, Hawaii, Indiana, Maine, Michigan, Minnesota, New Hampshire, New Mexico, Oregon, Rhode Island, Vermont, West Virginia and Washington, D.C. Another 9 states have only one institution each (Arizona, Delaware, Idaho, Montana, Nevada, North Dakota, South Dakota, Utah and Wyoming). Since 1960, 205 of 354 state institutions have been closed, according to the University of Minnesota's Research and Training Center on Community Living.

Case Success Story – Near National Adoption of National Core Indicators

Since this report was first introduced in 2006, UCP has made it a priority for states to utilize a significant quality assurance program. The National Core Indicators (NCI) from the Human Services Research Institute has been that gold standard.

Appreciating this, the Obama administration has provided even more funding and incentives for states to participate. UCP's decade-plus focus, combined with these federal incentives, have had a profound impact.

In 2006 just 24 states participated in NCI. Today, 46 states and DC do (all of the states other than Iowa, Montana, North Dakota, and West Virginia, although WV has participated in the past).

Why is this important? While other reports can give broad stats on where people are living, whether they are working and if they receive family support, NCI gives us person-level information on saety, participation in the community, and a detailed life experience. Think of it like the difference between a restaurant inspection score and Yelp or Google reviews. The former tells one basic information. The latter gives on insight into the ***actual*** experience of people dining there.

SERVING THOSE IN NEED

4 **27 states, up from 26, now report meeting the 80 percent Home-Like Setting standard,** which means that at least 80 percent of all individuals with ID/DD are served in settings such as their own home, a family home, family foster care or small group settings like shared apartments with fewer than four residents. The U.S. average for this standard is 80 percent. Just eleven (up from 8) states meet a top-performing 90 percent Home-like Setting standard: Alaska, Arizona, California, Colorado, D.C., Michigan, Nevada, New Hampshire, Vermont, Washington, and Wisconsin.

5 **Fifteen states, up from ten last year, report at least 10 percent of individuals using self-directed services,** according to the National Core Indicators survey in 36 States. Five states report at least 20 percent being self-directed. These states include: Florida, Illinois, New Hampshire, Utah and Vermont.

TRACKING HEALTH, SAFETY AND QUALITY OF LIFE

6 **47 states, up from 42 last year, participate in the National Core Indicators (NCI) survey,** a comprehensive quality-assurance program that includes standard measurements to assess outcomes of services. A total of 36 states, up from 29 last year, reported data outcomes in 2015.

KEEPING FAMILIES TOGETHER

7 **Only 15 states, up from 14 last year, report that they are supporting a large share of families through family support (at least 200 families per 100,000 of population).** These support services provide assistance to families that are caring for children with disabilities at home, which helps keep families together, and people with disabilities living in a community setting. These family-focused state programs were in: Arizona, California, Delaware, Louisiana, Minnesota, Montana, New Hampshire, New Mexico, New York, Pennsylvania, South Carolina, South Dakota, Vermont, Wisconsin, and Wyoming.

PROMOTING PRODUCTIVITY

8 **10 states, up from 8 last year, report having at least 33 percent of individuals with ID/DD working in competitive employment.** These states include: Connecticut, Maryland, New Hampshire, New Mexico, Oklahoma, Oregon, Rhode Island, Vermont, Washington, and West Virginia.

9 **15 states report successfully placing at least 60 percent of individuals in vocational rehabilitation in jobs,** with nineteen states reporting the average number of hours worked for those individuals placed being at least 25 hours and four states reporting at least half of those served getting a job within one year. No states met the standard on all three success measures.

PROMOTING PRODUCTIVITY

10 **Waiting lists for residential and community services are high and show the unmet need.** Almost 350,000 people, 28,000 more than last year, are on a waiting list for Home and Community-Based Services. This requires a daunting 46 percent increase in states' HCBS programs. 18 states, an increase from 16 last year, report no waiting list or a small waiting list (requiring less than 10 percent program growth).

2016 *THE CASE FOR INCLUSION* RANKINGS

By Ranking

State	2016 Ranking	2015 Ranking
Arizona	1	1
Vermont	2	21
New Hampshire	3	25
Michigan	4	29
Hawaii	5	5
California	6	16
District of Columbia	7	8
Missouri	8	3
South Dakota	9	38
Maryland	10	2
Colorado	11	6
Minnesota	12	7
New York	13	4
South Carolina	14	9
Delware	15	35
Ohio	16	10
Maine	17	12
Oregon	18	18
Kentucky	19	19
Indiana	20	23
Pennsylvania	21	22
Alabama	22	13
Georgia	23	11
Utah	24	15
Kansas	25	20
Massachusetts	26	14
Connecticut	27	17

State	2016 Ranking	2015 Ranking
Washington	28	26
Florida	29	27
Alaska	30	40
Wisconsin	31	33
Louisiana	32	24
West Virginia	33	30
New Jersey	34	28
Tennessee	35	32
Rhode Island	36	39
Nevada	37	31
North Carolina	38	34
Virginia	39	41
New Mexico	40	36
Nebraska	41	37
Idaho	42	46
Wyoming	43	45
Oklahoma	44	43
Iowa	45	44
North Dakota	46	42
Illinois	47	47
Montana	48	48
Arkansas	49	49
Texas	50	50
Mississippi	51	51

2016 *THE CASE FOR INCLUSION* RANKINGS

Alphabetical

State	2016 Ranking	2015 Ranking
Alabama	22	13
Alaska	30	40
Arizona	1	1
Arkansas	49	49
California	6	16
Colorado	11	6
Connecticut	27	17
Delaware	15	35
Dist. of Columbia	7	8
Florida	29	27
Georgia	23	11
Hawaii	5	5
Idaho	42	46
Illinois	47	47
Indiana	20	23
Iowa	45	44
Kansas	25	20
Kentucky	19	19
Louisiana	32	24
Maine	17	12
Maryland	10	2
Massachusetts	26	14
Michigan	4	29
Minnesota	12	7
Mississippi	51	51
Missouri	8	3
Montana	48	48

State	2016 Ranking	2015 Ranking
Nebraska	41	37
Nevada	37	31
New Hampshire	3	25
New Jersey	34	28
New Mexico	40	36
New York	13	4
North Carolina	38	34
North Dakota	46	42
Ohio	16	10
Oklahoma	44	43
Oregon	18	18
Pennsylvania	21	22
Rhode Island	36	39
South Carolina	14	9
South Dakota	9	38
Tennessee	35	32
Texas	50	50
Utah	24	15
Vermont	2	21
Virginia	39	41
Washington	28	26
West Virginia	33	30
Wisconsin	31	33
Wyoming	43	45

A Resource for Media

Frequently throughout the year, UCP receives media inquiries about the ***Case for Inclusion*** report, its data, and what it means.

Reporters want facts and also context. This report provides both.

Often times, these reporters may call to better understand the ranking or what it means. By the time the interview is done, these reporters have a better sense of what is working and what needs improvement in a state. This perspective often leads to positive stories on what's working (which helps to protect those gains) and exposes what needs improvement (which focuses policymakers on fixing it).

A great recent example of this comes from Washington, D.C. Martin Austermuhle of WAMU 88.5 FM (Public Radio) produced a four-part radio and video series called "From Institution to Inclusion: For D.C. residents with developmental disabilities, it's been a decades-long fight to be treated like everyone else."

The series began highlighting the stark reality of institutionalization and ended with a call to action to focus on competitive employment as the next "inclusion" advancement.

This series shows the power of the ***Case for Inclusion***. With context, facts, and in-depth case studies, the reporter had the information to do his own investigative series to really dig into the reality of services and outcomes-- both past and present-- in the nation's capital.

Without the ***Case for Inclusion***, this report could have been a one-and- done story. With the rankings and data, it was a multi-part exposé ending with a forward-looking, positive call to action. As a result, policymakers, members of the public, and advocates have a new resource and greater awareness about the importance of inclusion and how to advance inclusion even more.

SUB-RANKING BY MAJOR CATEGORY

Although the overall ranking presents a comprehensive view of each state and the District of Columbia, it is also important to consider the top-performing states in each of the five major categories in addition to how improvement in any category would have the biggest impact on better state performance and subsequent ranking. For example, Arizona ranks #1 overall, but ranks low (sub-ranking #41) for promoting productivity. Arizona could potentially learn from Washington State (sub-ranking #1) how it can improve in this area.

	Promoting Independence		Tracking Health, Safety & Quality of Life		Keeping Families Together		Promoting Productivity		Reaching Those in Need		Overall	
	50% of total		*14% of total*		*8% of total*		*12% of total*		*16% of total*		*100%*	
	Score	Rank	Score	Rank	Score	Rank	Score	Rank	Score	Rank	Score	Rank
Alabama	43.9	13	11.5	3	1.7	41	4.5	50	10.0	40	71.6	22
Alaska	46.7	6	0.0	39	2.3	34	7.1	12	12.2	22	68.2	30
Arizona	46.9	4	10.7	25	7.1	1	6.4	27	14.3	5	85.5	1
Arkansas	26.4	50	10.9	19	1.3	46	6.1	36	10.8	35	55.6	49
California	43.8	14	10.8	22	4.5	10	6.9	16	14.9	2	81.0	6
Colorado	44.9	9	10.7	26	1.2	48	7.8	6	11.8	26	76.4	11
Connecticut	37.4	39	11.4	6	3.3	22	7.3	9	9.8	41	69.2	27
Delaware	40.1	29	10.9	20	4.0	15	5.6	47	13.5	8	74.1	15
District of Columbia	42.9	17	11.7	2	2.4	33	7.5	8	13.4	10	77.8	7

SUB-RANKING BY MAJOR CATEGORY (CONTD.)

	Promoting Independence		Tracking Health, Safety & Quality of Life		Keeping Families Together		Promoting Productivity		Reaching Those in Need		Overall	
	50% of total		*14% of total*		*8% of total*		*12% of total*		*16% of total*		*100%*	
	Score	Rank	Score	Rank	Score	Rank	Score	Rank	Score	Rank	Score	Rank
Florida	40.8	27	11.0	12	3.0	27	3.3	51	10.3	38	68.3	29
Georgia	43.9	12	11.3	9	1.5	44	5.5	48	8.8	46	71.0	23
Hawaii	46.8	5	11.1	11	5.3	7	4.8	49	13.2	12	81.2	5
Idaho	39.2	35	0.0	39	1.1	51	6.0	38	13.1	14	59.4	42
Illinois	26.8	49	11.0	15	1.6	42	5.6	46	10.7	36	55.8	47
Indiana	39.4	33	11.4	7	2.6	31	6.7	23	12.2	20	72.2	20
Iowa	36.8	40	0.0	39	1.5	45	6.2	30	14.2	6	58.8	45
Kansas	40.0	30	10.3	32	2.0	37	6.4	28	12.1	23	70.9	25
Kentucky	42.1	22	11.3	10	1.2	50	6.0	40	11.8	27	72.3	19
Louisiana	35.0	43	10.7	28	6.3	4	6.2	32	9.3	45	67.5	32
Maine	42.7	18	10.6	30	1.3	47	6.0	39	12.4	18	73.0	17
Maryland	44.6	10	10.7	27	1.2	49	8.1	4	12.0	24	76.6	10
Massachusetts	41.0	25	10.9	21	1.9	40	6.9	18	10.8	39	70.9	26
Michigan	47.3	3	10.1	36	3.7	17	7.0	15	13.2	13	81.3	4
Minnesota	42.4	21	11.0	16	5.3	6	6.7	22	11.0	33	76.3	12
Mississippi	9.3	51	2.5	37	2.1	35	5.7	45	10.7	37	30.2	51
Missouri	42.5	19	10.6	29	4.5	11	7.0	14	12.8	16	77.5	8
Montana	34.4	45	0.0	39	3.2	24	6.1	35	11.9	25	55.7	48
Nebraska	40.6	28	0.0	39	1.9	39	7.2	11	12.3	19	62.0	41
Nevada	45.2	8	0.0	39	3.0	26	7.2	10	9.5	44	65.0	37
New Hampshire	48.4	2	10.7	24	2.8	28	7.1	13	13.0	15	82.1	3
New Jersey	33.2	47	11.0	16	2.4	32	5.8	44	13.3	11	65.8	34
New Mexico	44.1	11	2.2	38	2.8	29	6.8	19	7.0	48	63.0	40
New York	39.4	36	10.5	31	4.2	14	6.4	29	15.5	1	76.0	13
North Carolina	31.5	48	10.9	18	4.4	13	6.6	24	10.8	34	64.3	38
North Dakota	35.7	41	0.0	39	1.9	38	5.9	42	14.3	4	57.9	46
Ohio	39.7	32	10.3	35	5.9	5	6.1	37	11.5	30	73.4	16
Oklahoma	34.5	44	10.9	17	2.1	36	6.2	31	5.5	49	59.2	44
Oregon	46.1	7	0.0	39	4.5	12	7.8	5	14.0	7	72.4	18
Pennsylvania	41.1	24	11.3	8	3.4	19	6.1	34	9.8	42	71.8	21

SUB-RANKING BY MAJOR CATEGORY (CONTD.)

	Promoting Independence		Tracking Health, Safety & Quality of Life		Keeping Families Together		Promoting Productivity		Reaching Those in Need		Overall	
	50% of total		*14% of total*		*8% of total*		*12% of total*		*16% of total*		*100%*	
	Score	Rank	Score	Rank	Score	Rank	Score	Rank	Score	Rank	Score	Rank
Rhode Island	43.0	16	0.0	39	2.6	30	6.2	33	16.5	9	65.2	36
South Carolina	38.5	36	11.5	4	6.4	3	6.8	21	11.4	31	74.5	14
South Dakota	38.0	38	11.4	5	5.1	8	7.7	7	14.5	3	76.7	9
Tennessee	40.8	26	12.2	1	1.6	43	6.6	25	4.6	50	65.8	35
Texas	33.3	46	10.8	23	3.4	21	5.9	43	0.9	51	54.2	50
Utah	38.4	37	10.3	33	3.6	18	6.9	17	11.8	28	71.0	24
Vermont	49.1	1	10.3	33	3.9	16	8.6	2	11.0	32	83.0	2
Virginia	35.2	42	11.0	14	3.2	25	6.8	20	7.2	47	63.3	39
Washington	41.5	23	0.0	39	4.8	9	10.1	1	12.8	17	69.1	28
West Virginia	42.5	20	0.0	39	3.3	23	8.1	3	12.2	21	66.1	33
Wisconsin	43.4	15	0.0	39	7.1	2	5.9	41	11.7	29	68.1	31
Wyoming	39.7	32	0.0	39	3.4	20	6.5	26	9.7	43	59.3	43

MOST IMPROVED, AND BIGGEST DROPS, SINCE 2007

Over the last decade much has changed in the states. To highlight these changes—both good and bad—below is a table showing those states with the biggest improvement since 2007 as well as those states with the greatest drop in their ranking. A brief explanation as to what caused these changes in each state follows the table.

	2016	2007	Difference 07-16
IMPROVED			
Dist. of Columbia	7	49	42
Missouri	8	41	33
Ohio	16	48	32
Maryland	10	33	23
Kentucky	19	40	21
Indiana	20	37	17
South Dakota	9	26	17
DROPPED			
Idaho	16	29	-17
West Virginia	39	25	-17
Connecticut	37	22	-21
Massachusetts	22	6	-22
Wyoming	36	19	-26
New Mexico	38	18	-27
Alaska	23	2	-28
Montana	29	8	-29

MOST IMPROVED STATES

↑42 PLACES

District of Columbia

Reports a significant increase in the share of individuals (from 44 percent to 82 percent) and resources (from 10 percent to 64 percent) dedicated to those receiving home and community-based services. Now reports 93% of those served are in home-like settings.

↑33 PLACES

Missouri

Substantially increased the portion of resources dedicated to people in the community (from 50 percent to 88 percent), dramatically increased the portion of people served in home-like settings (from 75 percent to 84 percent), closed the last two state institutions, started participating and reporting outcomes for the NCI.

↑32 PLACES

Ohio

Dramatically increased the portion of resources dedicated to people in the community (from 50 percent to 65 percent) as well as the share of individuals served in the community (from 63 percent to 84 percent), closed a state institution (reducing by more than half the portion of individuals served in large institutions from 18 percent to 6 percent), started participating in and reporting outcomes for the NCI.

↑23 PLACES

Maryland

Substantially increased the portion of resources dedicated to people in the community (from 86 percent to 99 percent), dramatically increased the portion of people served in home-like settings (from 74 percent to 82 percent), closed the last two state institutions, started participating and reporting outcomes for the NCI.

↑21 PLACES

Kentucky

Reports an increase in the share of individuals (from 79 percent to 97 percent) and resources (from 63 percent to 79 percent) dedicated to the community, and reduced the population at state institutions by 39 percent. In 2008, Kentucky also added a Medicaid Buy In program to support coverage when individuals work and increase their income.

↑17 PLACES

Indiana

Reports an increase in the share of individuals (from 70 percent to 89 percent) and resources (from 54 percent to 67 percent) dedicated to the community and also closed 5 state institutions. In addition, Indiana receives high marks on the National Core Indicators quality outcomes, which were added to the ranking beginning in 2014.

↑17 PLACES

South Dakota

Primarily improved its ranking as a direct result of its high marks on the National Core Indicators quality outcomes, which were added to the ranking beginning in 2014.

STATES WITH THE BIGGEST DROPS

↓29 PLACES

Montana

Reported a significant (38 percentage point) reduction in the portion of individuals served in home-like settings (from 80 percent to 42 percent) and does not participate in the NCI.

↓29 PLACES

Alaska

Fell dramatically because the number of people being served in a family home was previously estimated (by the state) at 3,700 for the 2007 ranking. Beginning with the 2010 ranking, it was reported accurately and is now at around 332 people served in a family home. Alaska now participates in NCI, but outcomes will not be available until next year.

↓27 PLACES

New Mexico

Primarily dropped due to not reporting on all outcomes measures on the NCI.

↓26 PLACES

Wyoming

Primarily dropped in the ranking because the state just started participating in the NCI, but data will only become available for scoring in next year's ranking. Also, the state had a drop in competitive employment (from 25 percent to 18 percent) and remained stagnant while most other states improved overall causing the state to fall in comparison to others.

↓22 PLACES

Massachusetts

Primarily dropped in the rankings as direct result in the drop in the portion of people served in home-like settings (from 76 percent to 65 percent) and a drop in competitive employment (from 43 percent to 29 percent).

↓21 PLACES

Connecticut

Primarily dropped in the rankings due to a decline in the portion served in home-like settings (from 71 percent to 58 percent) and a drop of 65 percent in number of families served by Family Support. While CT remained flat in competitive employment at about 50 percent, the top scoring state (now Washington State) dramatically improved to 86 percent, meaning Connecticut lost ground (and points) to the top performers.

STATES WITH THE BIGGEST DROPS

17 PLACES

West Virginia

Primarily dropped in the rankings due to the fact that it does not participate in NCI.

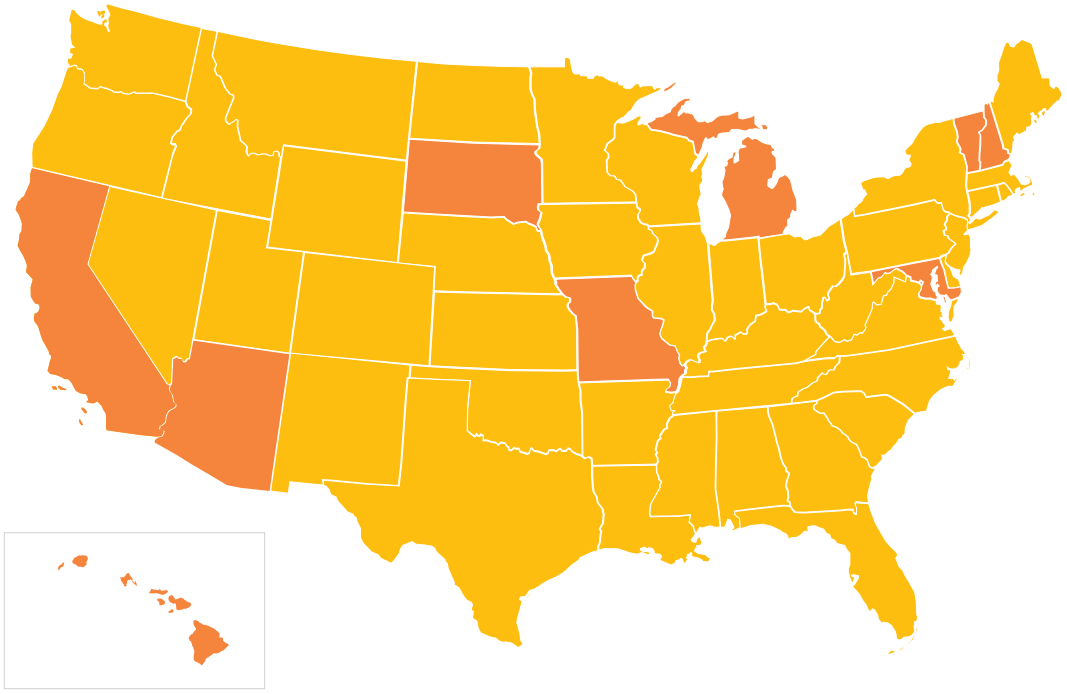
17 PLACES

Idaho

Increased the share of individuals (from 75 percent to 93 percent) but only slightly increased the share of resources (from 51 percent to 68 percent) dedicated to community based services. Significantly reduced the portion of individuals served in home-like settings (from 92 percent to 81 percent), and now participates in the NCI but data on outcomes will not be reported until the 2017 ranking.

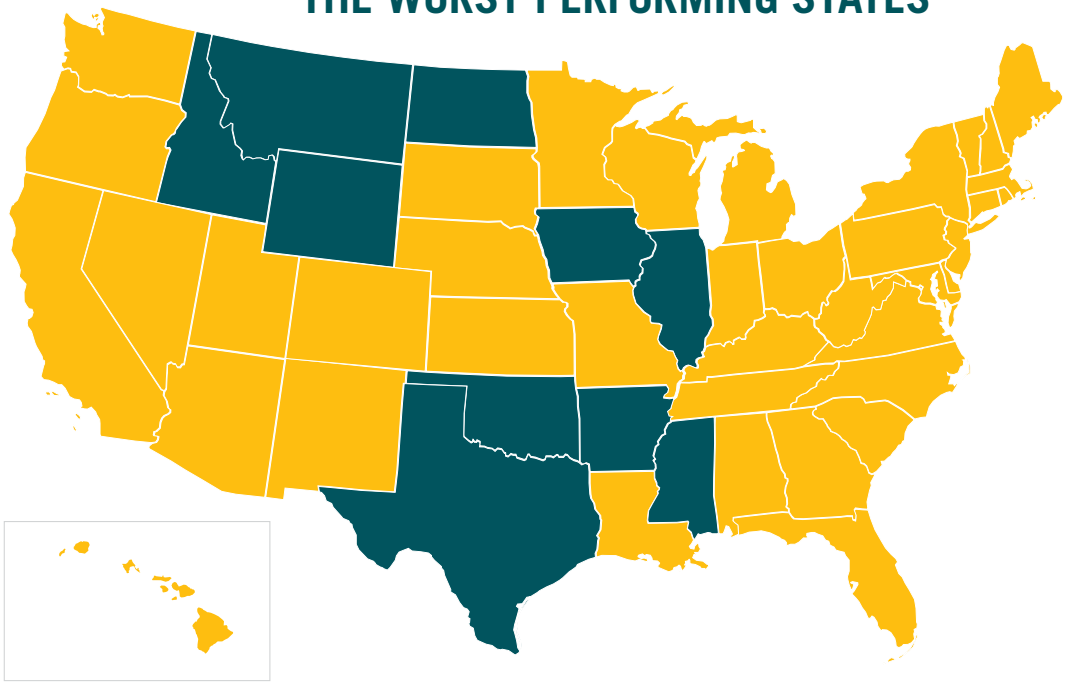
THE BEST, THE BOTTOM, AND FACTS ABOUT THE TOP 10 PERFORMING STATES

THE BEST PERFORMING STATES



1 Arizona
2 Vermont
3 New Hampshire
4 Michigan
5 Hawaii
6 California
7 Dist. of Columbia
8 Missouri
9 South Dakota
10 Maryland

THE WORST PERFORMING STATES



42 Idaho
43 Wyoming
44 Oklahoma
45 Iowa
46 North Dakota
47 Illinois
48 Montana
49 Arkansas
50 Texas
51 Mississippi

FACTS ABOUT THE BEST PERFORMING STATES

1. **Top Performers are both big and small states in population**—"big" population states include California (biggest) and Michigan (#9) as well as "small" population states such as South Dakota (#46), Vermont (#50) and the District of Columbia (#49).

2. **Top Performers are both rich and poor states in terms of median family income**—"rich" states include Maryland (richest), New Hampshire (2nd richest), Hawaii (3rd richest), and D.C. (5th richest) and less affluent states such as Arizona (#38), South Dakota (#31) and Michigan (#32).

3. **Top Performers are high tax and low tax burden states**—"high tax burden" states include California (#6, tied), D.C. (#10) and Maryland (#6, tied) and "low tax burden" states include Arizona (#37), New Hampshire (#45), and South Dakota (#49).

4. **Top Performers are big and low spenders per person served through Home and Community-Based Services**—"big spender" states are Vermont (#16) and D.C. (#2) and "low spender" states include Arizona (#49), California (#48), Michigan (#42), and South Dakota (#45).

5. While Top Performers tended to trend more politically Democratic, with seven of the top ten being Blue states (according to their 2012 Presidential Election results), three Red states were in the top ten showing some political diversity.

Population and Median Family Income data is from the Kaiser Family Foundation using U.S. Census Bureau data. Tax burden data is from the Tax Foundation. And spending data is from Research and Training Center's RISP 2016 Report.

HOW TO USE THIS *THE CASE FOR INCLUSION* & HOW THE RANKINGS WERE DEVELOPED

USING *THE CASE FOR INCLUSION* REPORT

This report puts each state's progress in serving individuals with intellectual and developmental disabilities into a national context. It is intended to help advocates and policymakers understand:

1. **How their state performs overall in serving individuals with intellectual and developmental disabilities;**
2. **What services and outcomes need attention and improvement in their state; and**
3. **Which states are top performers in key areas, so advocates and officials in those top-performing states can act as a resource for those states desiring to improve in key areas.**

Advocates should use this information to educate other advocates, care and service providers, families and individuals, policymakers and state administrations on key achievements and areas needing improvement within each state. The facts and figures can support policy reforms and frame debates about resource allocation for the ID/DD population. Advocates can also use the information to prioritize those areas that need the most immediate attention and use the facts to support adequate and ongoing funding to maintain high quality outcomes, eliminate waiting lists and close large institutions.

Elected officials should use this report as a guiding document on which issues in their community needs their time and attention and, possibly, additional resources or more inclusive state policies to improve outcomes for individuals with intellectual and developmental disabilities.

Those within federal and state administrations should use this report to put their work and accomplishments in context, and to chart a course for the next focus area in the quest for continuous improvement and improved quality of life. UCP also advocates that government agencies should replicate this data reporting in more detail at the state and county level to identify areas of excellence and to target critical issues needing attention.

HOW THE RANKINGS WERE DEVELOPED:

The Case for Inclusion rankings were developed through a broad, data-driven effort. Demographic, cost, utilization, key data elements and outcomes statistics were assembled for all 50 States and the District of Columbia. Ninety-nine individual data elements from numerous governmental non-profit and advocacy organizations were reviewed. Dozens of Medicaid, disability and ID/DD policy experts were consulted as well as members of national advocacy and research organizations. They were asked to consider the attributes of top performing Medicaid programs, and offer opinions and recommendations on key data measures and outcomes.

To comprehensively determine the top-performing states, a weighted scoring methodology was developed. Thirty key outcome measures and data elements were selected and individually scored in five major categories on a total 100-point scale. If a person is living in the community, it is a key indicator of inclusion; therefore, the "Promoting Independence" category received half of all possible points.

The top-performing state for each measure was assigned the highest possible score in that category. The worst-performing state was assigned a zero score in that category.

WEIGHTING OF *CASE FOR INCLUSION* SCORES– 100 TOTAL POSSIBLE POINTS

Category	Measure		Points Assigned	
Promoting Independence	Community-Based	% of Recipients with ID/DD on HCBS	9	50
		% of ID/DD Expenditures on HCBS	7	
		% of ID/DD Expenditures on non-ICF-MR	8	
	Residential Services in the Community (includes all types)	1-3 Residents - %	13	
		1-6 Residents -%	11	
		16+ Residents % (smaller %, higher rank)	-4	
		% in Large State Facilities	-3	
	NCI - % Self-Directed		2	
Tracking Health, Safety & Quality of Life	Quality Assurance - NCI Participation		0	14
	NCI - Recent Dental Visit		2.8	
	NCI - Lonely Less than Half the Time		2.8	
	NCI - Not Scared in Own Home		2.8	
	NCI - Inclusion (sum of 4 measures)		2.8	
	NCI - Relationships Other than Staff and Family		2.8	
Keeping Families Together	Family Support per 100k		3	8
	% in a Family Home		3	
	NCI - Child/Family Survey Participation		2	
Promoting Productivity	Has Medicaid Buy-In Program		2	12
	Competitive Employment - %		4.0	
	Voc Rehab - Rehab Rate (finding a job)		2	
	Voc Rehab - Number of Hours Worked		2	
	Voc Rehab - Retain Job for One Year		2	
Reaching Those in Need	Waiting List - Average % Growth for Residential and HCBS		9	16
	Individuals with ID/DD Served per 100k of Population		2	
	Ratio of Prevalence to Individuals Served		2	
	Uses Federal Functional Definition for Eligibility or Broader		3	
				100

WEIGHTING OF *CASE FOR INCLUSION* SCORES– 100 TOTAL POSSIBLE POINTS (CONTD.)

2016 Data Source	2016 Table
RTC	Calculated from fiscal reporting
RTC	Calculated from fiscal reporting
Coleman	State Profiles
RTC	Table 1.1
RTC	Table 1.3
RTC	Table 1.4
RTC	Table 1.5
NCI	Table 43
NCI	Table 86
NCI	Table 63
NCI	Table 106
NCI	Table B2, B30, B32, B34
NCI	Table 58
Coleman	State Profiles
Coleman	State Profiles
NCI	2012, 2013 Participating Stores
Mathematica	Table B.3
ICI	Table 5
ICI	Table 8
ICI	Table 8
ICI	Table 8
RTC Kaiser	Table 1.6 ID/DD Wait List
RTC	Calculated
Census	Table 1810
NASDDS	Table 1

In general, the top-performing state for each measure was assigned the highest possible score in that category. The bottom-performing state was assigned a zero score in that category. All other states were apportioned accordingly based on their outcome between the top- and worst-performing.

As noted, most data is from 2014, but all data is the most recently available from credible national sources. Much of the data is self-reported by the states. These state rankings are a snapshot in time, and policy changes or reforms enacted or beginning in 2015 or later would not yet have an impact on the data.

When reviewing an individual state's ranking, it is important to consider action taken since 2014, if any, to accurately understand both where that state was and where it is presently. Especially given the implementation of Home and Community Based Waivers. It is important to note that not all individuals with disabilities were considered, only those with intellectual and developmental disabilities. This limited the scope of the effort, allowing focus on subsequent initiatives of meaningful, achievable improvement.

A note of caution: although more than 55 points separate the top performing state from the poorest performing state, 9 points separate the top 10 states, 15 points separate the top 25 states and only 11 points separate the middle 25 states. Therefore, minor changes in state policy or outcomes could significantly affect how a state ranks on future or past *Case for Inclusion* reports. This fact alone should also further incentivize state advocates and policy makers into action, as small and incremental changes continue to have a lasting impact on quality of life for individuals with disabilities in communities across the country.

Data Sources

Census – U.S. Census Bureau's Annual Community Survey 2014.

Coleman - The Coleman Institute for Cognitive Disabilities, University of Colorado - The State of the States in Developmental Disabilities' state profiles (through fiscal year 2013).

ICI – University of Massachusetts' Institute for Community Inclusion – StateData: The National Report on Employment Services and Outcomes 2015.

Kaiser – Kaiser Family Foundation's State Indicators – Waiting Lists for HCBS Waivers 2014.

Mathematica – Mathematica's Enrollment, Employment, and Earnings in the Medicaid Buy-In Program, 2011

NASDDDS - National Association of State Directors of Developmental Disabilities Services and Rutgers Center for State Health Policy - State Strategies for Determining Eligibility and Level of Care for ICF/MR and Waiver Program Participants 2008.

NCI – Human Services Research Institute's National Core Indicators Adult Consumer Survey for FY 2014-2015 and Child Family Survey for FY 2012-2013, FY 2013-2014 and FY 2014-2015.

RTC – University of Minnesota's Research and Training Center's - In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends Through 2012 - Residential Information Systems Project (RISP) – advance copies of the 2016 report provided to UCP. The 2015 report is available online.

ACKNOWLEDGEMENTS

A special thank you to Sheryl A. Larson, Senior Research Associate at the University of Minnesota's Research and Training Center on Community Living, who again provided an advance copy of data tables for their 2016 report. It should be noted that the Research and Training Center's data is drawn from their own surveys of state developmental disability directors but, when these directors do not or are not able to respond with the requested information, then data is drawn from Coleman Institute, Kaiser Family Foundation and American Health Care Association reports as well.

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1. The University of Minnesota Research and Training Center on Community Living. "Medicaid Home and Community Based Services for Persons with Intellectual and Developmental Disabilities – Interim Report." September 26, 2005. Page 3.

ABOUT THE AUTHOR:

Tarren Bragdon

Tarren Bragdon has been involved in healthcare policy research and analysis for more than a decade. His work has been featured in newspapers and media outlets nationwide including *The Wall Street Journal*, *New York Post*, *New York Sun* and PBS. He served two terms in the Maine House of Representatives on the Health and Human Services Committee and served as chair of the board of directors of Spurwink Services, one of the largest social service providers in Maine.

ABOUT UNITED CEREBRAL PALSY

United Cerebral Palsy (UCP) educates, advocates and provides support services through an affiliate network to ensure a life without limits for people with a spectrum of disabilities. Together with nearly 70 affiliates, UCP has a mission to advance the independence, productivity and full citizenship of people with disabilities by supporting more than 176,000 children and adults every day—one person at a time, one family at a time. UCP works to enact real change—to revolutionize care, raise standards of living and create opportunities—impacting the lives of millions living with disabilities. For more than 60 years, UCP has worked to ensure the inclusion of individuals with disabilities in every facet of society. Together, with parents and caregivers, UCP will continue to push for the social, legal and technological changes that increase accessibility and independence, allowing people with disabilities to dream their own dreams, for the next 60 years, and beyond.

Please visit our website, www.ucp.org for additional resources in your area, or contact us (800) 872-5827 to learn more about UCP.

1825 K Street NW Suite 600 Washington, D.C. 20006

National Reports on State Intellectual Disability Systems

In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends Through 2014

https://risp.umn.edu/

State Data: The National Report on Employment Services and Outcomes 2015

https://www.statedata.info/sites/statedata.info/files/files/statedatabook_2015%20_Final.pdf

The State of the States in Intellectual and Developmental Disabilities

http://www.stateofthestates.org/

Integrating Research, Training, and Knowledge Translation

What our new center is about

- People with intellectual and developmental disabilities (IDD) can work and want to work--yet the majority don't have jobs.
- State and national policies exist to increase employment, but systems have not aligned to make integrated employment a priority.
- To meet this need, the Institute for Community Inclusion (ICI) at UMass Boston is hosting a new rehabilitation research and training center, or RRTC. It's called the **RRTC on Advancing Employment for Individuals with Intellectual and Developmental Disabilities.**
- Because change is critical at multiple levels, the RRTC integrates four focus areas:
  1) individual and family knowledge and engagement,
  2) effective employment supports,
  3 organizational change for community rehabilitation providers, and
  4) state-level policy and strategy.
- In 2015, our products and activities include a webinar series featuring innovative and inspiring speakers, policy papers that target state administrators and individuals with IDD, a review of effective strategies for communicating with families, in-depth interviews with employment consultants about the strategies used to help people find jobs, and findings from a panel of experts about what comprises a "high-performing" community rehabilitation provider.

Background on employment and disability

Since the introduction of supported employment in the Developmental Disabilities Act of 1984 and the Rehabilitation Act Amendments of 1986, there has been continued development and refinement of best practices in employment services and supports. Progress includes demonstrations of creative outcomes for individuals with significant support needs, including customized jobs and self-employment, community rehabilitation providers that have shifted emphasis to integrated employment, and states that have made a substantial investment in Employment First policy and strategy.

What is Employment First?

» **States that adopt an Employment First policy focus on employment in individual integrated jobs in the typical labor market as the preferred option for all citizens with disabilities. This means that employment is the priority for funding, individual planning, and the supports an individual receives.**

Despite these achievements, the promise of integrated employment has not been realized for many individuals with IDD. The number of individuals supported in integrated employment by state IDD agencies has remained stagnant for the past fifteen years, participation in non-work services has grown rapidly, and individual employment supports are not implemented with fidelity to a consistent model or expectations.[1]

What does the data tell us?

There is no direct source for data on labor force participation for individuals with IDD in the general population. However, data from the National Core Indicators Project suggests that, in 2012–2013, only 15% of working-age adults supported by state IDD agencies worked in integrated employment, including both individual and group supported employment, with just 10% working in individual competitive or supported jobs.[2]

Other ICI survey research estimates that 18% of individuals receiving day supports from state IDD agencies participated in integrated employment services during FY2013. This percent has declined from a peak of almost 25% in FY2001. Those who are employed typically work limited hours with low wages.[3] American Community Survey data (2012) shows that people with a cognitive disability who are receiving Supplemental Security Income, the group most likely to include people who have the most significant cognitive disabilities, have the lowest employment rate of all disability subgroups. They are also the most likely to live in a household that is below the poverty line.[4]

How have national and state-level policies responded?

The 2014 Workforce Innovation and Opportunity Act (WIOA) requires that each state public vocational

By the Numbers

4 ... PERCENT OF JOB DEVELOPERS' TIME THAT IS SPENT WITH EMPLOYERS

6 ... NUMBER OF STATES REPORTING 40% OR MORE OF INDIVIDUALS SERVED IN INTEGRATED EMPLOYMENT SERVICES

9 ... PERCENT OF CRP STAFF WORKING ON INTEGRATED EMPLOYMENT

12 ... AVERAGE HOURS (PER PERSON) WORKED PER WEEK IN AN INDIVIDUAL SUPPORTED JOB

13.5 ... PERCENT OF IDD AGENCY DAY AND EMPLOYMENT FUNDING SPENT ON INTEGRATED EMPLOYMENT

15 ... PERCENT OF INDIVIDUALS WORKING IN INTEGRATED EMPLOYMENT

18 ... PERCENT OF INDIVIDUALS PARTICIPATING IN AN INTEGRATED EMPLOYMENT SERVICE (OF THOSE RECEIVING A DAY SERVICE FROM STATE IDD AGENCIES)

43 ... PERCENT OF INDIVIDUALS WHO ARE IN NON-WORK SERVICES

44 ... NUMBER OF STATES THAT HAVE SOME FORM OF EMPLOYMENT FIRST INITIATIVE

47 ... PERCENT OF INDIVIDUALS WHO DON'T WORK WHO SAY THEY WANT TO WORK.

rehabilitation program focus on transition services and pre-employment services, coordinate with the state agency responsible for administering the state Medicaid plan and with state IDD agencies, and address access to the general workforce development system and One-Stop Career Centers (American Job Centers) for people with disabilities.

In 2011, the Centers for Medicare and Medicaid Services (CMS) released guidance clarifying their commitment to individual integrated employment as a preferred outcome of employment-related services under the home and community-based services waiver program. In January 2014, CMS released new rules about home and community-based setting requirements. The new rules specify that states must prioritize access to community living in the most integrated setting; additional guidance related to the assessment of community-based employment settings is forthcoming.

The U.S. Department of Justice has extended enforcement of the Olmstead decision to address employment outcomes in states including Rhode Island, Oregon, Georgia, and Virginia. This places pressure on all states to move individuals from segregated settings to more community-based models of support. The Rhode Island settlement agreement establishes strong standards for employment participation, quality employment outcomes, and access to integrated community activities during non-work hours.[5]

At least 44 states have some form of Employment First initiative, and 32 have a formal state-level policy or directive,[6] which is nationally recognized as a policy path towards integrated employment for people with IDD. Employment First policy establishes clear guiding principles and practices through state statute, regulation, and operational procedures. Employment First represents a commitment by states to the propositions that all individuals with IDD (a) are capable of performing work in typical integrated employment settings; (b) should receive, as a matter of state policy, employment-related services and supports as a priority over facility-based and non work day services; and (c) should be paid at minimum or prevailing wage rates.[7]

Six causes of poor employment outcomes

State IDD agencies have inconsistent and competing priorities.

#1

State IDD agencies remain the primary source of long-term funding and service coordination, including managing Medicaid Home and Community-Based Services waivers. The agencies provide, fund, and monitor a wide range of services, including employment supports, facility-based options (sheltered workshops and non-work day habilitation programs), community integration services, and self-directed supports.

State IDD agency investment in integrated employment varies widely, with between 5% and 86% of all individuals participating in integrated employment services. Despite the national mean of 18% in integrated employment, six states report that over 40% of individuals participate in integrated employment, suggesting substantial opportunity for policy change and redirection of resources.

Non-work services are growing and competing with integrated employment.

#2

Participation in non-work services is growing. While the most common service of this type is day habilitation (facility-based non-work), concern for a meaningful day has led to growth in supports for community-based non-work and community life engagement. These services compete with integrated employment for resources[8] and have grown steadily for state IDD agencies that report non-work as a service.[9]

Survey research found that 16.4% of individuals with IDD participate in community-based non-work services.[10] These services are loosely defined with respect to requirements, activities, populations served, and goals, which further complicates prioritizing resources.[11]

Interagency integration of services is limited.

#3

Navigating employment services is confusing for individuals and families, and not well coordinated by state agencies. Despite mandates for interagency collaboration, research finds that mechanisms for information-sharing and shared service delivery are not well coordinated. There are gaps in service delivery, a lack of agreement about target populations, and differences in culture and resources.[12]

The Government Accountability Office highlighted as barriers the difficulty students and their parents face navigating services across different programs during the transition to adult life, limited coordination across agencies, and a lack of information about the full range of service options available after high school.[13]

Individuals and families lack accurate knowledge to make informed choices.

#4

Young adults with IDD express a strong expectation that they will work in adulthood,[14] and almost 50% of adults served by state IDD agencies who are not working say that they want an integrated job.[15] This preference is rooted in the principles of self-determination and informed choice,[16] and is expressed regardless of the severity of disability.[17] Collectively, self-advocates have made integrated employment ("real jobs") a stated national policy objective, citing work as a hallmark of inclusion in society.[18]

Families can be influential in the decision-making process.[19] Research has shown that people with IDD are most likely to be employed when their parents want them to and believe they can work,[20] and that parental expectation was the most predictive factor of paid work experience.[21] Despite findings that emphasize family engagement, research shows that parents lacked adequate knowledge to support their child's transition to adult life. Family factors found to influence outcomes include lack of information about work incentives and fear of losing benefits.[22] In fact, such misinformation negatively impacts the expectations of parents about work in general.[23]

Community rehabilitation providers' priorities have not re-aligned to emphasize employment.

#5

Community rehabilitation providers (CRPs) and their staff are the primary source of day and employment supports for people with IDD. Survey findings reveal that only 8.7% of CRP staff have time dedicated to integrated employment.[24] Continued service and philosophical variation within the provider community makes the creation of a unified vision for service delivery difficult.[25]

Research shows that almost 89% of respondents to a national survey of CRP administrators believe that facility-based programs are essential for individuals with disabilities who are having difficulty getting or maintaining real work in the labor force, and only 47% had a formal plan to expand integrated employment.[26] Providers perceive inadequate funding and community resources for individual employment.[27] Front-line staff experience confusion about job development responsibilities, do not feel prepared to engage the mainstream business community, and have little training in providing appropriate supports to individuals with IDD in community settings.[28]

Best practices in job supports are not consistently implemented.

#6

The successful transition of job seekers to employment depends in large part on the knowledge, skills, and abilities of employment consultants to develop, match, and support jobs that meet both the job seeker's and the employer's interests and needs.[29] Research suggests that employment consultants inconsistently use established promising practices, including investing in discovery or career planning, spending time with individuals in community settings, working with families, and negotiating job responsibilities with an employer.[30]

Findings also suggest that job developers have limited opportunities for professional development, including both formal and informal chances for learning.[31] However, employment specialists who do receive appropriate training and mentorship improve the number and quality of the jobs they develop.[32]

How will our new center address these issues?

The field of IDD is at a crossroads. More than three decades of research by the ICI has found that integrated employment outcomes only improve if all policies and practices are aligned to support employment as the first goal for service recipients, and if individuals and families have clear and useful access to information and supports.[33]

To help make integrated employment a real option for all adults with IDD, our new RRTC will integrate research, dissemination, and knowledge translation. The center will:

- Develop and test a comprehensive information, outreach, and support framework for individuals and families.
- Assess a cost-effective strategy for improving employment support practices by integrating online training, data-based performance feedback, and facilitated peer supports.
- Develop and test an evidence-based intervention to support organizational transformation and resource rebalancing across networks of CRPs.
- Analyze state employment systems' policies and practices and their relationship to individual outcomes at a multi-agency level, and define policies and practices of high-performing state employment systems.

The center is part of a rich network of research and systems change initiatives, including ICI's consulting relationships with 45 states and the extensive work of partners including The Arc of the United States, the University of Minnesota, the National Association of State Directors of Developmental Disabilities Services (NASDDDS), Self-Advocates Becoming Empowered (SABE), and APSE (the Association of People Supporting Employment First). Participation of a network of advisors and dissemination partners, including people with IDD and their families, will extend the effectiveness and use of our project findings and resources.

What's next?

For the 2015 project year, products and activities include:

- The launch of a social media campaign and website.
- A webinar series that features innovative and inspiring leaders in our field.
- A detailed review of strategies for individual and family engagement and knowledge translation.
- Qualitative interviews with employment consultants about their use of evidence-based strategies for helping job seekers find employment.
- Policy papers from our partners at NASDDDS and SABE.
- A Delphi panel around organizational transformation of CRPs.

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ThinkWork!

Advancing employment and opportunity for people with intellectual and developmental disabilities

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CRP Organizational Change

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Introduction

Federal and state policy shifts have opened the doors to meaningful community employment for individuals with intellectual/developmental disabilities (IDD). Progress is apparent across the country: creative outcomes for individuals with significant support needs through customized jobs and self-employment, innovative practices at the provider level, and state investment in an Employment First philosophy.

Despite these achievements, the number of individuals supported in integrated employment by state agencies that serve individuals with IDD has remained the same since 2000.[1] While some community rehabilitation providers (CRPs) across the country have transformed their services to focus on integrated employment, including closing facility-based programs,[2] most have not yet reallocated resources to promote gainful community employment as a top priority.

This brief:

- Describes the national landscape regarding employment supports provided by community rehabilitation providers.
- Introduces a new line of research that documents and facilitates transformation efforts that will lead to greater community employment options for individuals with IDD.

What is the level of prioritization on community employment across CRPs?

CRPs and their staff are the primary source of day and employment supports for people with IDD. To understand the extent to which CRPs prioritize employment, we consider two types of data: the percentage or number of direct support staff working in CRPs who provide employment supports, and the number or percentage of people with IDD who receive employment supports from CRPs.

A 2009 ICI survey found that only approximately 9% of CRP staff are dedicated to integrated employment.[3] ICI's 2010–2011 National CRP Survey found that 19% of individuals with IDD participated in individual employment services, only a slight increase from the 18% reported in 2002–2003. The majority of individuals participated in facility-based or non-work services (25% and 43%, respectively), and the largest growth area was in non-work services, from 33% to 43%.

Research suggests continued variation of services and employment philosophies within the provider community. Inge et al. (2009) found that almost 89% of respondents to a national survey of CRP administrators believe that facility-based programs are essential for individuals with disabilities who are having difficulty getting or maintaining real work in the labor force, and less than half of these administrators had a formal plan to expand integrated employment. Providers perceive inadequate funding and community resources to provide individual employment.[4]

Within the organizations themselves, front-line staff experience confusion about job development responsibilities, do not feel prepared to engage the mainstream business community, and have little training in providing appropriate supports to individuals with IDD in community settings.[5]

What do we know about CRPs' organizational transformation?

While research citing the barriers experienced by CRPs is plentiful, findings on the essential elements for providing high-quality CRP programs and services are more limited. The Training and Technical Assistance for Providers (T-TAP) project identified six characteristics of CRPs that successfully expanded employment opportunities:[6]

1) Clear and uncompromising goals
2) Communication of expectations through policy and outreach activities
3) Reallocation and restructuring of resources
4) Rapid job placement one person at a time
5) Development of community partnerships
6) Planning for the whole person with wrap-around life supports

How will this project support CRPs to evolve their service delivery framework?

Through the work of the Rehabilitation Research and Training Center on Advancing Employment for Individuals with Intellectual and Developmental Disabilities, we propose a holistic evaluation and expansion of the framework for CRP performance to facilitate and measure

large-scale organizational change. This research will support CRPs to reallocate organizational resources toward individual integrated employment.

Building from existing ICI research and technical assistance, this line of research will:

1) create and assess a model framework for building the capacity of CRPs,
2) develop a toolkit to guide organizational transformation to provide high-quality integrated employment services, and
3) demonstrate an efficient scalable strategy (a facilitated, peer-to-peer learning community) for supporting organizational transformation across networks of CRPs.

Project activities will be implemented in collaboration with CRPs affiliated with The Arc, a national leader in disability rights and advocacy.

What's next?

We will use a Delphi process (a research strategy to obtain a reliable group opinion from a pool of experts) to initially identify, define, and refine the six observable standards for evaluating CRP performance. The goal of the Delphi process is to validate previous T-TAP findings with an expert population in order to increase the fidelity of the framework. Members of the Delphi panel will include self-advocates, family members, researchers, state administrators, and providers.

Once this process is completed in the spring of 2015, project staff will conduct case study research of CRPs that have successfully transformed services to prioritize individual integrated employment. Findings from this research will be used to validate and refine the existing framework.

What's the goal?

» **Develop a strategy for supporting community rehabilitation providers to rebalance resources to emphasize individual integrated employment.**

How will we get there?

» **Develop a framework and toolkit to enable CRPs to provide greater access to integrated employment supports.**

» **Test a scalable facilitated peer learning community as a strategy for supporting CRP self- assessment and organizational change.**

Our research questions:

» **What are the characteristics of CRPs that have transformed services to emphasize high-quality integrated employment?**

» **What organizational, state, and community factors influence organizational transformation?**

» **What is the impact of a facilitated peer network of providers on rebalancing of resources and employment outcomes?**

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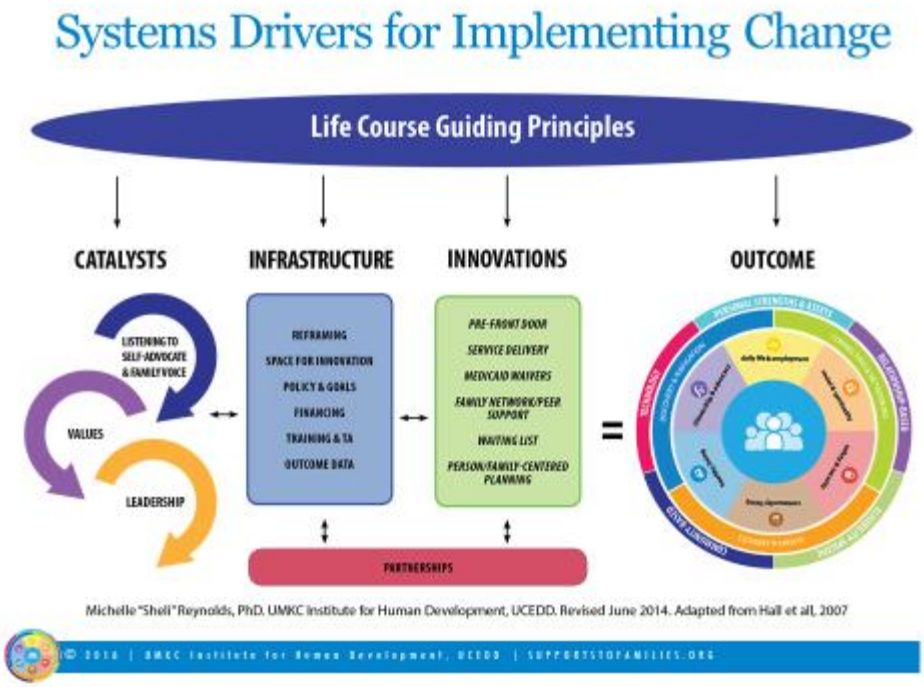
National Community of Practices for Supporting Families of Individuals of I/DD Across the LifeSpan

The National Community of Practice for Supporting Families of Individuals of I/DD originally began in 2012 as a project funded by the Administration for Intellectual and Developmental Disabilities. Connecticut, District of Columbia (DC), Oklahoma, Tennessee, Washington and Missouri (as the mentor state), to build capacity through a community of practice across and within these states to create policies, practices and systems to better assist and support families that include a member with I/DD across the lifespan.

Participating states have changed the front door into the system, improved cultural considerations in supporting families, guided and influenced policymakers and helped shape waivers and other Medicaid authorities to focus on supporting families and individuals throughout the lifespan. The National Association of State Directors of Developmental Disabilities Services (NASDDDS), along with the University of Missouri Kansas City Institute for Human Development (UMKC IHD), partner to support states, work to impact national policies, develop products and tools, and provide technical assistance.

In July 2016, eleven (10) new states joined the CoP in addition to the original states. While each state approach varies, all participate with the mutual commitment to support the goals identified in the 2011 Wingspread Family Support Summit which is as follows, “Overall Goal of Providing Support: The overall goal of supporting families with all of their complexity and diversity, is to maximize their capacity, strengths, and unique abilities so they can best support, nurture, love and facilitate opportunities for the achievement of self-determination, interdependence, productivity, integration, and inclusion in all facets of community life.”

The CoP uses a framework for systems change adapted from the State Employment Leadership Network (SELN) (see below). The outcome of systems change is supports that help individuals and families achieve a good quality of life. Systems change is driven by innovations in supports offered to families, changes in infrastructure that make it more effective and flexible, and partnerships with organizations and the community. Family and self-advocate voices, values, and leadership are the catalysts that add fuel to the fire and make systems change more personal. Finally, all of this change is happening under the umbrella of the LifeCourse framework, which promotes the idea that all people have the right to live, love, work, play and pursue their life aspirations in the community. Learn more about the LifeCourse framework at lifecoursetools.com.



The service delivery system for people with disabilities has a history of discrimination and segregation, denying access to many opportunities for individuals with I/DD. Based on this historical discrimination, a change in the culture is necessary for system reform. As societal perception changes about people with disabilities so must the systems and policies designed to support them. The main catalyst for this change is listening to the self-advocate and family voice. Secondary catalysts include leadership and the value that segregation and discrimination is no longer acceptable. These catalysts nudge the system towards change.

Key to system reform is systems efficiency. Disability service systems, through both state and federal programs, furnish a wide array of services and supports to individuals with I/DD. These services and supports provide opportunities for individuals with I/DD to maximize their full potential and participate in their families and community. The state disability system must drive forward innovative services, such as family specific strategies and family- and person- driven services.

Another consideration for system reform is the fact that the new system must effectively facilitate collaboration and use of community assets. There are three strategies in family support that emphasize collaboration and use of current assets the family and community possess, these strategies are: discovery and navigation, connecting and networking, and goods and services.

The interplay of all these aspects come together in the community, and form the outcome of supporting families with a member with a disability across the life course.

SUPPORTING FAMILIES
of individuals with intellectual & developmental disabilities
THE NATIONAL COMMUNITY OF PRACTICE • FUNDED BY THE ADMINISTRATION ON INTELLECTUAL & DEVELOPMENTAL DISABILITIES
CONNECTICUT STATE TEAM

Context

Connecticut Department of Developmental Services (DDS) served approximately 16,000 youth and adults with intellectual disabilities (ID) in 2015 through five HCBS Waivers: Comprehensive Support, Individual and Family Support, Employment and Supports, Home and Community Supports for Persons with Autism, and Early Childhood Autism Waiver. Current challenges in Connecticut include budget reductions and wait lists for services. Initiatives underway in the state include responding to federal and state policies including the HCBS Settings Rule, No Wrong Door, Balancing Incentives Program, and Person-Centered Planning for older adults accessing Department on Aging Services.

Goals

- Embed LifeCourse principles and practices in DDS services planning and school planning processes and connect with person-centered planning practices.
- Increase use of technology and social networking strategies (example: Tyze) as valued supports.
- Increase options available for high quality employment, housing, out-of-home respite, and in-home, positive behavior, and peer supports.
- Create a culture of creative and effective family/community partnerships.

Anticipated Outcomes

- Policies, practices, and supports reflect the needs of individuals with IDD and their families due to the high level of stakeholder leadership in development.
- Individuals and families experience increased independence and flexibility in supports through the use of technology.
- Families and individuals have a secure and effective way to manage their day-to-day supports through the use of technology.
- Individuals and families experience increased connection and involvement in community through the availability of high quality support services.

Activities

Discovery & Navigation

- Developing and disseminating information through Community of Practice focus area committees and workgroups.
- Identifying what is working or not working with existing Discovery and Navigation processes.

Connecting & Networking

- Training family mentors on LifeCourse principles and tools.
- Implementing web-based option that helps organize a support network around an individual.
- Working with Family Support Network and Parent-to-Parent to disseminate the message of the LifeCourse framework statewide.

Goods & Services

- Including LifeCourse principles as part of core competencies in training for in-home support providers.
- Developing a matrix of person-centered planning and LifeCourse tools for case managers.
- Partnering with Safe and Smart Campaign and Tech Act to increase knowledge and availability of technology supports.

Hosted By

CT Council on Developmental Disabilities

CT Department of Developmental Services

Get Involved

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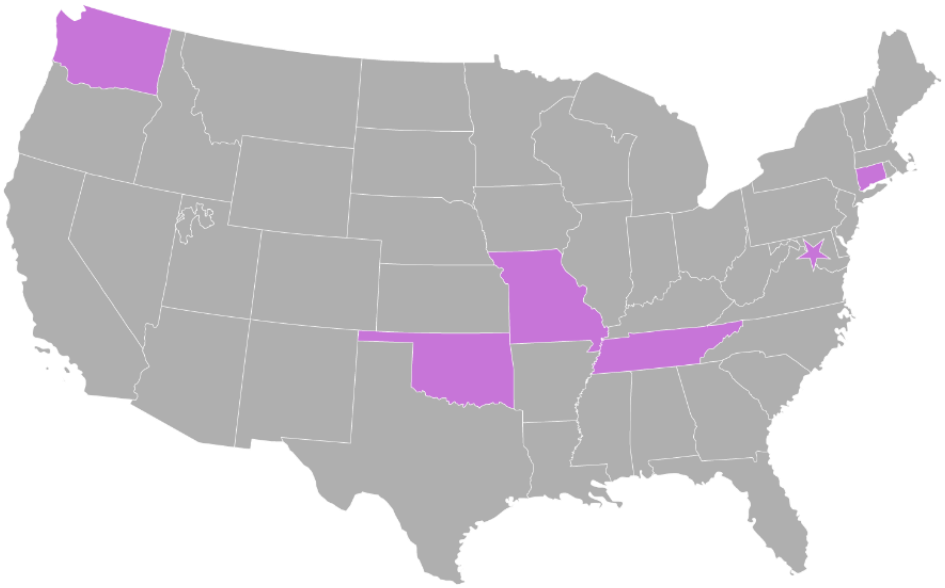
About the National Community of Practice



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States are focusing on policies and practices that reach across an individual's life span, think about all people with I/DD regardless of their connection to the formal systems, and work across agencies and communities to impact the trajectory of information.

Project Partners

UMKC Institute for Human Development
A University Center for Excellence in Developmental Disabilities

NASDDDS
National Association of State Directors of Developmental Disabilities Services

HSRI Human Services Research Institute

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DISTRICT OF COLUMBIA COP

Context

The District of Columbia Developmental Disabilities Administration (DDA) served approximately 2,250 adults with intellectual disabilities (ID) in 2015. DDA operates one comprehensive Home and Community Based Services (HCBS) Waiver for adults with ID. Initiatives underway include embedding Person-Centered Thinking and Employment First into services and supports, transformation of the Long Term Services and Supports System supported by a No Wrong Door implementation grant, and building supports for less restrictive alternatives to guardianship and commitment, such as Supported Decision-Making, and systems change to promote community integration and compliance with the HCBS Settings Rule.

Goals

- Community engagement with families not previously reached, as well as non-profit and government partners.
- High quality person and family-centered supports for people with ID, including a framework for self-direction and peer-supports throughout the lifespan.
- End civil commitment of people with ID, build alternatives to guardianship, and return decision-making to people with ID and their families.
- Plan to address service gaps, including comprehensive supports for people with developmental disabilities throughout the lifespan and coordination of services and supports for youth with ID.

Anticipated Outcomes

- Policies, practices, and supports reflect the needs of individuals with IDD and their families due to the high level of stakeholder leadership in development.
- Individuals and families experience increased independence and flexibility in supports through the use of technology.
- Families and individuals have a secure and effective way to manage their day-to-day supports through the use of social networking technology.
- Individuals and families experience increased connection and involvement in community through the availability of high quality support services.

Activities

Discovery & Navigation

- Created legislative authority for stipends to support involvement of people with ID and their families.
- Established Family Support Council to guide DC agencies that support people with ID and their families.
- Developed and widely distributed Advocacy across the Lifespan guide to build advocacy skills of families.
- Use Person-Centered Thinking to focus on strengths and shared responsibility for change.
- Share information through a listserv and community partners.

Connecting & Networking

- Establish and sustain DC Parent-to-Parent Chapter.
- Train families in Families Planning Together and the LifeCourse Framework.

Goods & Services

- Partner with No Wrong Door to improve front door experience at DDA.
- Incorporate the LifeCourse Framework into Individual Support Planning.
- Build Medicaid infrastructure for participant directed goods and services.
- Work with people with IDD and their families to develop an IFS waiver.

Hosted By

DC Department on Disability Services

DC Developmental Disabilities Council

Get Involved

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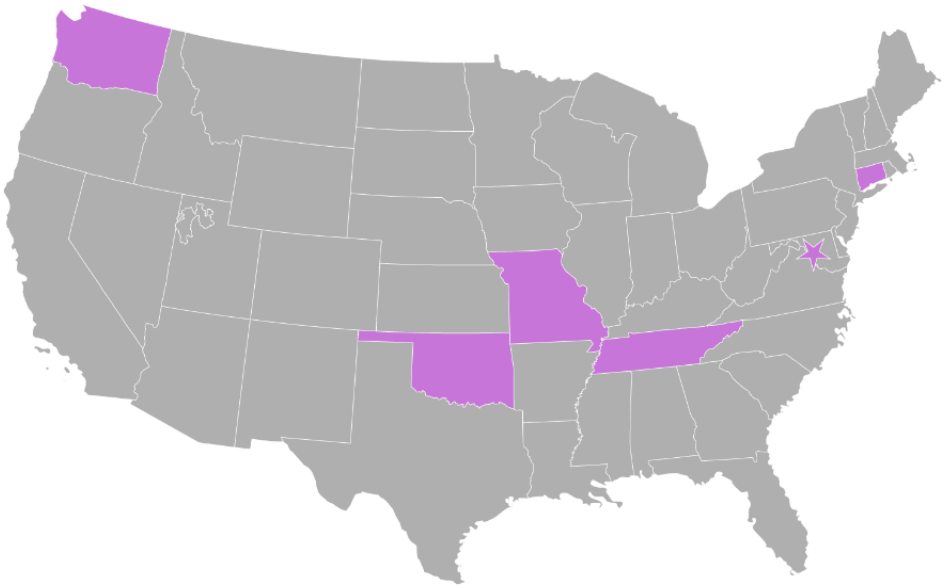
About the National Community of Practice



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MISSOURI STATE TEAM

Context

The Missouri Division of Developmental Disabilities (DDD) served approximately 17,400 individuals with intellectual and developmental disabilities (IDD) in 2015. An additional 16,000 individuals received Support Coordination only while waiting for services. DDD operates five HCBS Waivers including Comprehensive, Support, Children with Developmental Disabilities, Partnership for Hope, and Autism Waiver. Initiatives underway in Missouri include HCBS Settings Rule and Transition Plan, restructuring of the DDD Regional Offices, County Boards with authority to support flexibility and innovation, and expanded self-directed service options.

Goals

- Enhance stakeholder involvement in Community of Practice activities to include the voice of families and individuals with IDD.
- Improve information and resources for young people with disabilities to secure gainful employment and explore alternatives to guardianship
- Embed LifeCourse principles throughout DDD practices and supports.

Anticipated Outcomes

- Policies and practices to support individuals with IDD are influenced by themselves and their families in order to best meet their needs.
- Young adults with IDD have increased opportunities to lead a good life as they define it.
- Individuals with IDD and their families have increased access to information and tools to help them envision and actualize a good life in the community with the supports they need.

Activities

Discovery & Navigation

- Sustaining ten years of disseminating resource folder
- Including LifeCourse Transition handout and information about choice and guardianship alternatives with "Transfer of Rights" letter
- Infusing LifeCourse principles into Youth Leadership Academy
- Linking Community of Practice and Show Me Careers grant activities

Connecting & Networking

- Referring families directly to Missouri Family-to-Family network at intake
- Restructuring MO DD Council activities to align with LifeCourse principles
- Establishing a Family Network and Peer Support workgroup
- Training families and individuals with IDD on using LifeCourse tools for a good life

Goods & Services

- Updating DDD Quality Outcomes to align with LifeCourse principles.
- Embedding LifeCourse principles in Support Coordinator training and coaching.
- Piloting LifeCourse tools with County Boards.
- Training providers and direct care staff on LifeCourse principles.

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DIVISION OF DEVELOPMENTAL DISABILITIES

MODDC
MISSOURI DEVELOPMENTAL DISABILITIES COUNCIL

MISSOURI FAMILY TO FAMILY

Get Involved

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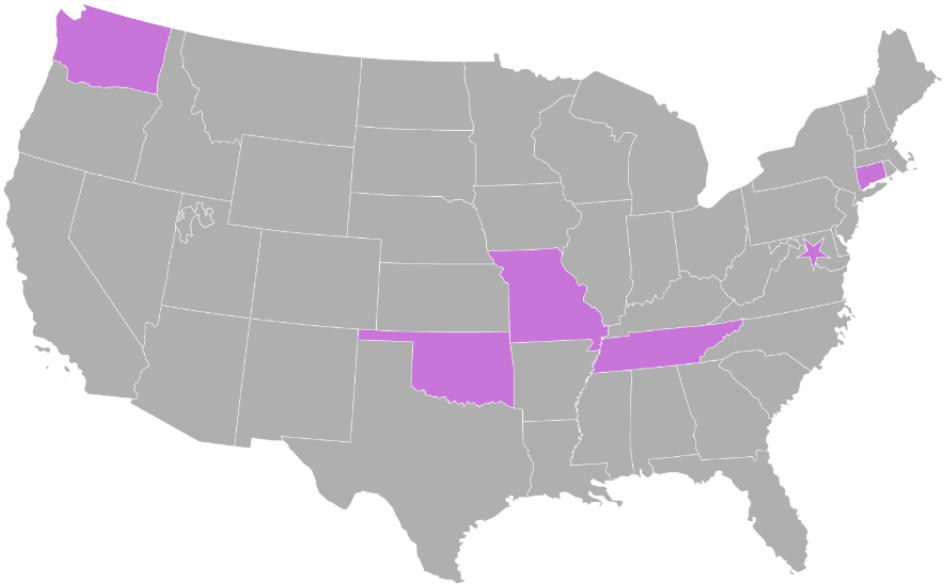
About the National Community of Practice



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States are focusing on policies and practices that reach across an individual's life span, think about all people with I/DD regardless of their connection to the formal systems, and work across agencies and communities to impact the trajectory of information.

Project Partners

UMKC INSTITUTE FOR HUMAN DEVELOPMENT
A University Center for Excellence in Developmental Disabilities

NASDDDS
National Association of State Directors of Developmental Disabilities Services

HSRI Human Services Research Institute

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SUPPORTING FAMILIES
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OKLAHOMA STATE TEAM

Context

Oklahoma (OK) Developmental Disabilities Services (DDS) served approximately 9,700 youth and adults with intellectual disabilities (ID) in 2015. DDS operates four Home and Community Based Services (HCBS) Waivers: Homeward Bound, Community Supports, and In-Home Supports Waiver (one for children, one for adults). OK experienced a state budget shortage of approximately $611 million and a decreased federal Medicaid matching funds rate in 2015; 2016 is facing a budget shortfall of $1 billion. Initiatives that could positively impact the current service system include the Governor's Blue Ribbon Panel to address the waiting list, the closure of the two remaining institutions for people with ID, Person-Centered Planning Training, and No Wrong Door.

Goals

- Expand understanding of the LifeCourse framework among individuals with IDD, families, and professionals.
- Increase the number and involvement of partners and stakeholders in Community of Practice activities.
- Incorporate LifeCourse planning tools in strategic planning at the individual, family, and systems levels.
- Expand capacity for training and technical assistance on LifeCourse tools statewide.
- Improve "front door" access to the service systems.

Anticipated Outcomes

- Recommendations generated by the Blue Ribbon Panel to address the waiting list reflect LifeCourse principles.
- LifeCourse principles are embedded in the culture of DDS and applied to strategic planning and problem-solving.
- Individuals and families are aware of and use the LifeCourse planning tools for achieving a good life with connections to community.
- Initial contact with DDS is easy to navigate and considers both formal and informal supports that best align with individual and family needs.
- Department of Human Services Child Welfare Division, the OK Autism Network, the OK Family Network, Sooner SUCCESS, and other agencies and organizations embed LifeCourse and Person-Centered Thinking concepts and tools in their work.

Activities

Discovery & Navigation

- Creating OK Good Life Video
- Disseminating resource folder and LifeCourse booklet
- Building OK Community of Practice website
- Developing strategic organizations plans that align with LifeCourse principles
- Developing and delivering specialized training to agencies and organizations statewide

Connecting & Networking

- Incorporating LifeCourse principles into Partners in Policymaking and Youth Leadership Forum.
- Incorporating LifeCourse information in keynote presentations and breakout sessions at Joining Forces, Governor's Conferences, and other local and statewide conferences and meetings.
- Training individuals and families on the LifeCourse framework through UCEDD's Family Support Center and Oklahoma Family Network.

Goods & Services

- Including strategies that align with LifeCourse principles in DDS contracts with agencies that serve individuals and families.
- Implementing the Integrated Star tool across agencies to aid with smooth transition between formal support systems.
- Enhancing person-centered planning practices by integrating the LifeCourse framework and tools into OK Person-Centered Learning Community.

Hosted By

OKLAHOMA DEVELOPMENTAL DISABILITIES COUNCIL

Oklahoma Department of Human Services
Developmental Disabilities Services

Center for Learning and Leadership
A University Center for Excellence in Developmental Disabilities
University of Oklahoma Health Sciences Center

Get Involved

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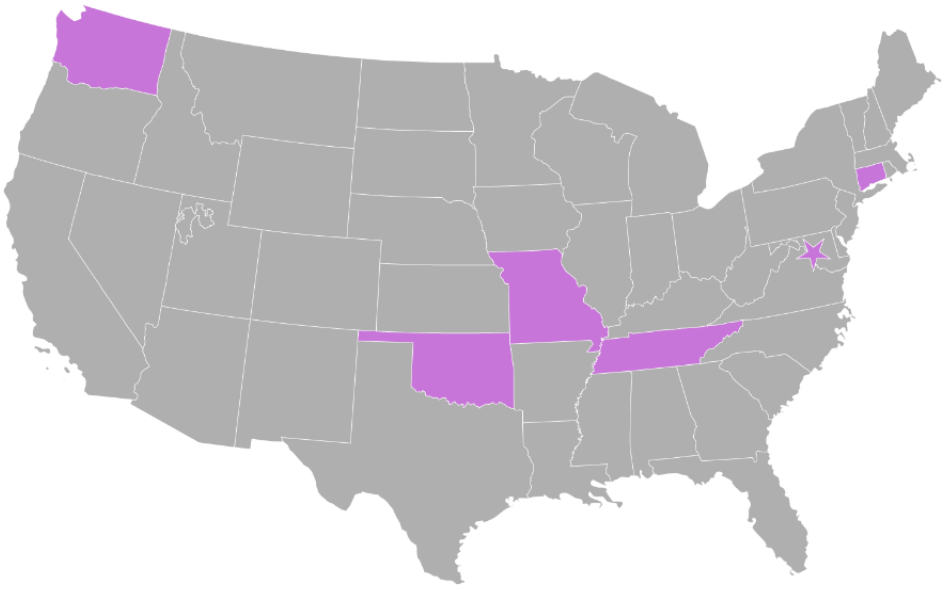
About the National Community of Practice



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Project

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TENNESSEE STATE TEAM

Context

Tennessee (TN) served approximately 8,000 individuals with intellectual and developmental disabilities (IDD) through three home and community based (HCBS) waivers offered by the Department of Intellectual and Developmental Disabilities' (DIDD). Current challenges in the state include wait lists for services and state budget reductions. Initiatives underway include responding to national and state policies, such as the HCBS Settings Rule, Aging Caregivers Act, ABLE Act Employment First Core State initiative (ODEP grant), and the Workforce Innovation and Opportunities Act (WIOA).

Goals

- Strengthen relationships with state agencies and community organizations who support families and individuals with IDD.
- Revise procedures related to first point of contact with service system to ensure that it is a meaningful encounter regardless of eligibility.
- Provide meaningful information and support to those on state agency waiting lists for services.
- Embed values and principles of LifeCourse and supporting families into daily business approach across state agencies.

Anticipated Outcomes

- Individuals and families are aware of and use the LifeCourse planning tools for achieving a good life with connections to community.
- LifeCourse principles are embedded in the culture of DDS and applied to strategic planning and problem-solving.
- System reforms that increase appropriate and flexible supports to families
- System-wide awareness of LifeCourse principles
- Integrated approach to supports across state agencies and community organizations guided by LifeCourse principles.

Activities

Discovery & Navigation

- Providing information through monthly Supporting Families e-newsletter and other communication tools
- Creating and disseminating "TN Kindred Stories Collection" to educate families and policymakers about experiences of families
- Disseminating the Community Resource Folder listing services and supports for individuals and families
- Incorporating LifeCourse information in keynote presentations and break-out sessions at TN Disability Megaconference

Connecting & Networking

- Collaborating with and strengthening the state sibling support network
- Increasing awareness of state peer mentoring initiatives

Goods & Services

- Implementing new DD waiver focused on employment services and support to families to be administered by managed care organizations (July 2016)
- Conducting "Lunch and Learn" events to share information and engage more partners
- Incorporating LifeCourse tools into intake assessment process
- Training managed care organizations on LifeCourse framework principles and tools
- Developing leadership academy for state personnel working in disability programs

Hosted By

TN Council on Developmental Disabilities

TN Department of Intellectual & Developmental Disabilities

Get Involved

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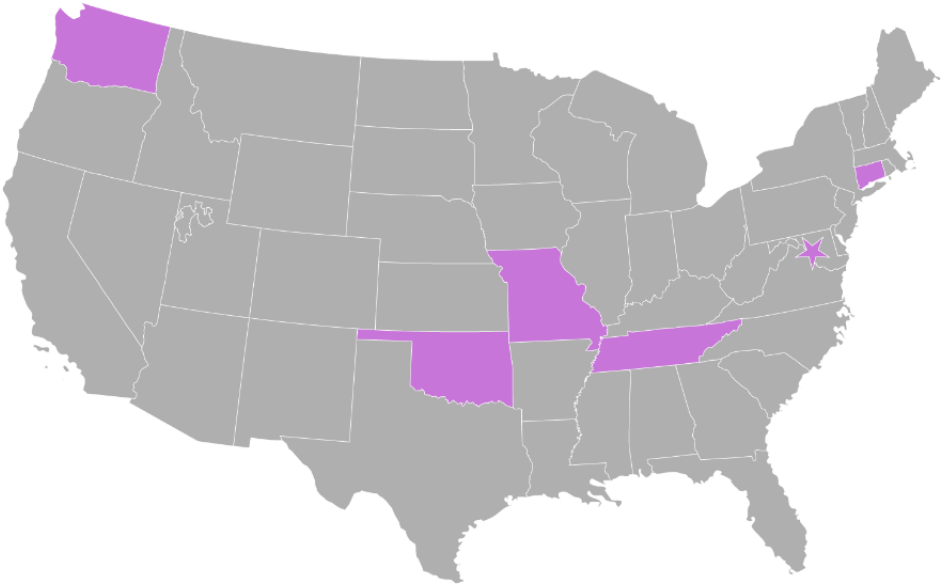
About the National Community of Practice



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Project

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WASHINGTON STATE TEAM

Context

The WA State Developmental Disabilities Administration (DDA) has a case load of 42,519 (September 2015) of which 28,328 adults and children with intellectual disabilities receive paid DDA services. Prior to 2015, the DDA operated four HCBS Waivers: Basic Plus, Core, Community Protection and Children's Intensive In-Home Behavioral Support Waiver. With funding from the 2014 Session, the Legislature authorized creating a new Individual and Family Support (IFS) Waiver to replace the state only funded Individual and Family Support program and creating a new Community First Choice Option under which all will receive Personal Care. DDA is now implementing the new IFS waiver with a goal of serving 5,000 people from the 14,191 on the No Paid Services Case Load.

Goals

- Develop effective and proactive strategies to address the needs of aging caregivers supporting family members.
- Establish adult sibling support network.
- Educate parents about parenting support services offered in the Individual and Family Support Waiver and make parents aware of the rights they have in the foster care and legal systems.
- Explore issues related to autonomy and self-determination for adults with IDD living with family.
- Improve the experience that individuals and families have with the first point of contact with DDA.

Anticipated Outcomes

- Families with aging caregivers receive supports that effectively meet their needs and assistance with planning for the future.
- Siblings of individuals with IDD have access to information, resources, and mutual support.
- Initial contact with DDA is easy to navigate and considers both formal and informal supports that best align with individual and family needs.
- Parents with IDD have effective supports to effectively manage their parenting role.

Activities

Discovery & Navigation

- Disseminating information via listserv and "Informing Families" initiative
- Implementing online person-centered planning tool, mylifeplan.guide, across life stages.
- Gathering information from particular stakeholder groups via surveys and focus groups.

Connecting & Networking

- Working with local and national sibling support groups to develop strategies to best support siblings of people with IDD.

Goods & Services

- Partnering with two counties to pilot approaches to improve the first point of contact with the service system.
- Participating in Smart Living Demonstration Project to explore technology support strategies.
- Integrating the online planning tool with person-centered service planning process.

Hosted By

WA State Developmental Disabilities Council

WA Developmental Disabilities Administration

Get Involved

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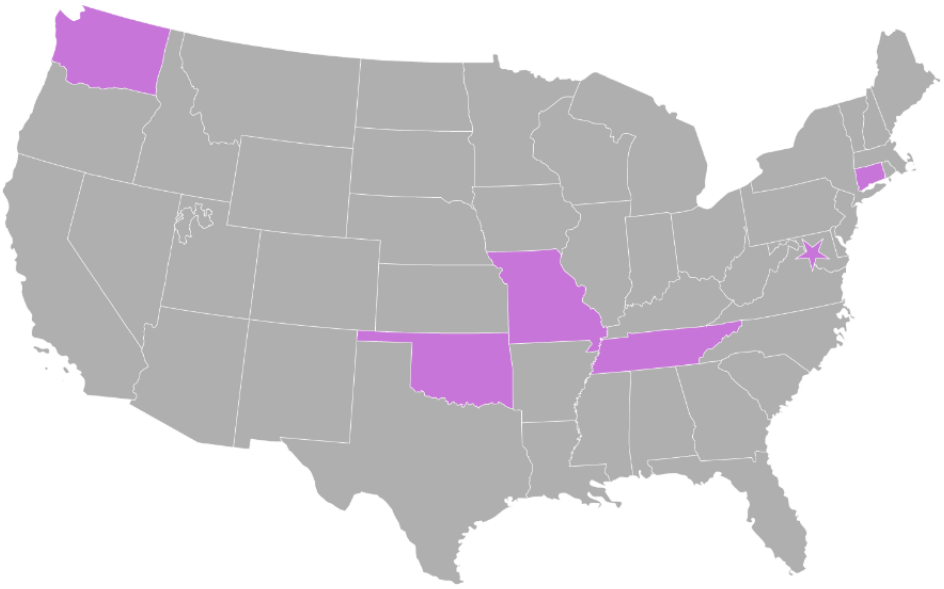
About the National Community of Practice



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