CABINET FOR HEALTH AND FAMILY SERVICES
DEPARTMENT FOR MEDICAID SERVICES

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M E M O R A N D U M

TO: Medicaid Managed Care Organizations

FROM: Lisa D. Lee, Commissioner

DATE: September 22, 2015

SUBJECT: 2015 Medicaid Managed Care Forums

Thank you for your support and participation in the 2015 Medicaid Managed Care Forums throughout the state. Our collaboration led to 5 successful forums that offered a venue for providers to meet face-to-face with members of your team and also served as an opportunity for us to hear from providers regarding specific issues and concerns. Three common topics emerged from the question and answer session at the forums and are outlined below.

Crossover Claims and Payments for Services Provided to Dual Eligible Individuals

The Department heard that crossover claims do not appear to be "crossing over" to the MCOs and that MCOs are not paying co-insurance and deductibles for dual eligible individuals. The Department requested that providers submit specific claims with details so we can identify and resolve these issues. The Department will be conducting research related to how our system is processing crossover claims to ensure that the appropriate information is being transmitted to MCOs. In addition, I ask that each MCO research and identify any issues related to transmission of crossover claims that may impact payment to providers. If issues are identified, please work through existing claims processing channels to correct.

Regarding payment of co-insurance and deductibles for services provided to dual eligible individuals, Section 30.4 of the current MCO contract reads:

> The Contractor shall coordinate benefits for Dual Eligible Members by paying the lesser amount of:

A. The Contractor's allowed amount minus the Medicare payment, or
B. The Medicare co-insurance and deductible up to Contractor's allowed amount.

In the event that Medicaid does not have a price for codes included on a crossover claim then the entire Medicare coinsurance and deductible shall be paid by the Contractor. The Contractor shall further assist Dual Eligible Members in coordination of benefits required under Section 4.3 "**Delegations of Authority**."

Each MCO shall make sure they are in compliance with this section. Any MCO found to be out of compliance will be issued a Corrective Action Plan.

Newborn MCO Assignments

The Department heard that the assignment of newborns to the mother's existing MCO creates an issue when the attending physician for the newborn does not accept the mother's MCO. We further heard that mothers may request a different MCO for their newborns but that request is not being honored. The Department is conducting research into this issue and requested specific information from providers. The Department will provide additional information to the MCOs, if necessary, regarding this issue and additional action that may be taken.

Retroactive MCO Changes

The Department heard concerns regarding changes in MCO plans with retroactive effective dates. The Department explained to attendees that the issue was related to several different eligibility systems at the state level and not due to action or inaction of the MCOs. We also informed attendees that the issue will be greatly reduced when the eligibility systems are merged this December.

Other common topics included length of time to credential providers, high MCO provider representative turnover, unable to reach MCO by phone, and inconsistent policy implementation within the same MCO.

Attached is an Excel spreadsheet with a dedicated sheet for each MCO. This spreadsheet contains a comprehensive listing of all providers who specifically requested that an MCO reach out to them. Please review the list and take necessary action to make contact with those requesting follow-up.

I believe we delivered valuable information to the provider community. In addition, questions and comments from the provider community can be used to assist both the Department and the MCOs in understanding and addressing provider issues and concerns. The purpose of the Medicaid program is to provide healthcare to some of our most vulnerable citizens. We cannot fulfill that purpose if we do not listen to our provider community and address issues and concerns in a timely manner. To that

end, the Department is compiling a list of questions with answers that will be posted on the DMS website soon. Each of you will receive a copy of the questions and answers as soon as it is completed.

Again, thank you for your participation at the 2015 Medicaid Managed Care forums. I look forward to future collaborations aimed at improving the Medicaid program and the services we deliver to our members. If you have questions or concerns related to this communication, please do not hesitate to contact me.

C: Cindy Arflack
Veronica Cecil
Neville Wise

Kentucky Medicaid MCO
Prior Authorization Request Form

Check the box of the plan in which the member is enrolled	MCO	Phone	Fax
	☐ Aetna Better Health of Kentucky		
	☐ Anthem BCBS Medicaid		
	☐ Humana – CareSource		
	☐ Passport Health Plan		
	☐ WellCare of Kentucky		

Not all plans require PAs for the same services. Check with the plan before submitting

Please complete all appropriate fields

Failure to provide sufficient information will result in a delay in your request

Date _____

Requesting Provider_____**Telephone #** _____ **NPI** _____

Medicaid ID # _____**Plan ID #** _____

Type of Request

☐ Pre-Service ☐ Post-Service ☐ Concurrent ☐ Urgent *Urgent is defined as 'significant impact to health of member'*

Member Information

Member Name_____Medicaid ID # _____ Plan ID#_____

Date of Birth_____ Is member Pregnant? ☐ Yes ☐ No

Work-related injury? ☐ Yes ☐ No Motor Vehicle Accident related injury? ☐ Yes ☐ No

Does member have other insurance? ☐ Yes ☐ No Medicare? ☐ Part A ☐ Part B Insurer _____

Rendering Provider Information

Servicing Provider _____NPI_____ Plan ID# _____

Address_____ Phone_____ Fax# _____

☐ Par ☐ Non-Par Are supporting documents included? ☐ Yes ☐ No Number of Documents_____

Type of Service

☐ Behavioral Health	☐ Gastric By-pass	☐ Medical Care - Outpatient	☐ Radiology
☐ Case Management	☐ Home Health	☐ Observation	☐ Surgical - Inpatient
☐ Dental Care	☐ Hospice	☐ OT/PT/ST	☐ Surgical - Outpatient
☐ DME Purchase	☐ Inhalation Therapy	☐ Oral Surgery	☐ Transportation
☐ DME Rental	☐ Maternity	☐ Private Duty Nursing	☐ Vision/Optometry
☐ EPSDT	☐ Medical Care - Inpatient	☐ Psychiatric	☐ **OTHER**

Clinical Information: Request **MUST** include medical documentation to be reviewed for medical necessity

Dates of Service		Procedure/ Service Codes	Diagnosis Code	Requested Service	Units/Visits
Start	Stop				

Additional Information: _____ _____ _____

_____ _____ _____

_____ _____ _____

_____ _____ _____

Signature of Qualified Practitioner _____ _____ Date _____

DRAFT

HUMAN SERVICE TRANSPORTATION DELIVERY PROGRAM (HSTD)

Overview:

The Human Service Transportation Delivery (HSTD) Program provides non-emergency, non-ambulance medical transportation services to eligible Medicaid, Vocational Rehabilitation, and Department of the Blind recipients. It also combines the resources of public and private transportation providers in an efficient, cost effective and easily accessible transportation program throughout the Commonwealth of Kentucky.

The Department for Medicaid Services (DMS) contracts with the Kentucky Transportation Cabinet (KyTC) to manage the daily operation of the HSTD program. The Office of Transportation Delivery (OTD) within the KyTC answers complaints from recipients, subcontractors, or regional brokers and resolves them. Please call 1-888-941-7433 if you need assistance with any issues or concerns.

A regional broker coordinates transportation services for each region through use of a network of providers located within the region.

Basic rules about transportation services:

If you or someone in your household has a car, van or truck and it is not available or appropriate for you to use, you must give the transportation provider, in writing, information that verifies you cannot use the vehicle.

- You can get a doctor's note if it is for a medical reason.
- You can get a mechanic's statement if it is not working or if there are mechanical problems.
- Have your family member's boss or school official write a note that the family member cannot give you a ride when you need it because of their work or school hours.
- If the car, van or truck has been junked, you will need to give a copy of the vehicle registration to your broker from the County Clerk's Office.

You should always try to go to the closet medical facility that can help your condition. If you need care that is out of your service area (county or a county that borders your county), you will need to have your doctor write a note to the broker explaining why it is important for the trip to occur.

Only Medicaid members that are in a wheelchair or are able to walk but disoriented are allowed to choose the company they want to ride with. You will need to give the broker a doctor's note saying that you need wheelchair or attendant services.

How to request services:

Recipients needing transportation services can contact their regional broker to inquire about their hours of operation and policies for scheduling transportation services. Normal transportation services must be scheduled with the regional broker 72 hours in advance. To cancel a reservation, please call the broker and not the Office of Transportation Delivery. After hours paging is available on weekends and state holidays for immediate or "urgent care" transportation needs. **To find your regional broker, please refer to http://transportation.ky.gov/Transportation-Delivery/Pages/Human-Service-Transportation-Delivery-Brokers.aspx**. We have also provided contact information for the Office of Transportation Delivery and regional brokers. The regional broker list is in alphabetical order by county.

OFFICE OF TRANSPORTATION DELIVERY
200 Mero Street
Frankfort, KY 40622
Phone: 888-941-7433
Fax: 502-564-2058

Human Service Transportation Delivery Brokers

Region	Counties	Broker	Toll Free Number	Phone Number	Website
1	Ballard, Calloway, Carlisle, Fulton, Graves, Hickman, Marshall, McCracken	Audubon Area Community Service, Inc. (GRITS)	1-844-575-9676		http://grits.audubon-area.com/index.php/medicaid-transportation
2	Caldwell, Christian, Crittenden, Hopkins, Livingston, Lyon, Muhlenberg, Todd, Trigg	Pennyrile Allied Community Services (PACS)	1-800-467-4601	(270) 886-6641	http://www.pacs-ky.org/
3	Daviess, Hancock, Henderson, McLean, Ohio, Union, Webster	Audubon Area Community Service, Inc. (GRITS)	1-800-816-3511	(270) 686-1651	http://grits.audubon-area.com/
4	Breckinridge, Grayson, Hardin, Larue, Marion, Meade, Nelson	LKLP Community Action Council (LKLP)	1-800-245-2826		http://www.lklp.org
5	Adair, Allen, Barren, Butler, Edmonson, Green, Hart, Logan, Metcalfe, Simpson, Taylor, Warren	LKLP Community Action Council (LKLP)	1-800-245-2826		http://www.lklp.org
6	Bullitt, Henry, Jefferson, Oldham, Shelby, Spencer, Trimble	Federated Transportation Services of the Bluegrass (FTSB)	1-888-848-0989		http://www.ftsb.org
8	Anderson, Boyle, Casey, Franklin, Garrard, Jessamine, Lincoln, Mercer, Scott, Washington, Woodford	Bluegrass Community Action Partnership (BGCAP)	1-800-456-6588	(502) 695-4290	http://www.bluegrasscommunityaction.org
9	Boone, Campbell, Carroll, Gallatin, Grant, Kenton, Pendleton and Owen	LKLP Community Action Council (LKLP)	1-800-245-2826		http://www.lklp.org
10	Fayette	Federated Transportation Services of the Bluegrass (FTSB)	1-888-848-0989	(859) 233-0066	http://www.ftsb.org
11	Bourbon, Clark, Estill, Harrison, Madison, Montgomery, Nicholas, and Powell	Federated Transportation Services of the Bluegrass (FTSB)	1-888-848-0989	(859) 233-0066	http://www.ftsb.org
12	Bell, Clinton, Cumberland, Knox, Laurel, McCreary, Monroe, Pulaski, Rockcastle, Russell, Wayne, Whitley	Rural Transit Enterprises Coordinated (RTEC)	1-800-321-7832	(606) 256-9835	http://www.4rtec.com
13	Breathitt, Clay, Harlan, Jackson, Knott, Lee, Leslie, Letcher, Owsley, Perry, and Wolfe	LKLP Community Action Council (LKLP)	1-800-245-2826	(606) 439-1362	http://www.lklp.org/
14	Floyd, Johnson, Magoffin, Martin, Pike	Sandy Valley Transportation Services (SVTS)	1-800-444-7433	(606) 886-1936	http://www.svtransport.org
15	Bath, Boyd, Carter, Elliott, Greenup, Lawrence, Menifee, Morgan and Rowan	LKLP Community Action Council (LKLP)	1-800-245-2826		http://www.lklp.org
16	Bracken, Robertson, Mason, Fleming, and Lewis	Licking Valley Community Action Program (LVCAP)	1-800-803-1310	1-800-327-5196	

2016

is the last year a provider can begin participation in the EHR Incentive Program. You could be missing out on $63,750.00 (over 6 years)!

Contact Us:
The Kentucky Medicaid EHR Incentive Program team may be contacted for more information. Office hours are Monday through Friday 8:00 am to 4:30 pm. Email us at EHRIncentives@ky.gov or call us at 502-564-0105 extension 2657.

http://chfs.ky.gov/dms/EHR.htm

KENTUCKY EHR | INCENTIVE PROGRAM

UCP United Cerebral Palsy™

the case for Inclusion 2015

UNITED CEREBRAL PALSY'S 2015 REPORT

INTRODUCTION

Every year since 2006, United Cerebral Palsy (UCP) produces The *Case for Inclusion*, an annual ranking of how well State Medicaid programs serve Americans with intellectual and developmental disabilities (ID/DD) and their families. Individuals with ID/DD, including the young and the aging, want and deserve the same opportunities and quality of life as all Americans.

Medicaid impacts so many—children and adults with disabilities, the elderly and families living in poverty. It is the critical safety net that provides financial and health care security and community support to Americans, including those with ID/DD, so their desired opportunities, quality of life and community participation can be fully realized.

It is both a duty and a necessity of a civil society such as ours to aid and empower these individuals, who are often the most vulnerable among us, to succeed. We are all stronger together.

Yet some States do much better than others in demonstrating the needed political will and sound policies 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; and, most importantly, the policies and practices of top performing States that may be considered as best practices.

MEDICAID FACT

TOTAL SPENDING (STATE AND FEDERAL) $432 BILLION

Individuals with ID/DD $40.7 billion (9.4%)

TOTAL ENROLLMENT 58.6 MILLION PEOPLE

Individuals with ID/DD 805,000 (1.4%)

Source: Most recent data available from FY2012 from the Medicaid 2013 Actuarial Report & the Research and Training Center on Community Living.

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 100 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.

FOUR KEY ASPECTS OF A HIGH FUNCTIONING MEDICAID PROGRAM

The University of Minnesota's Research and Training Center on Community Living 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.

The Case for Inclusion's major outcome areas align with a four-part holistic approach.

[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.

MAJOR ENHANCEMENTS IN 2014 AND MORE STATES' OUTCOME DATA FOR 2015

Since 2006, UCP's *Case for Inclusion* rankings have revealed how State's Medicaid programs measure up in areas including how many individuals are supported in the community, how many participate in competitive employment and family support services and how States are doing helping those in need, including serving those languishing on waiting lists.

Responding to feedback from UCP affiliates, policymakers and advocates asking for more person-centered, outcome-oriented measurements to showcase if and how individuals are faring as an active part of their community, UCP made several major enhancements to the 2014 *Case for Inclusion* report to take a closer look at how Americans with intellectual and developmental disabilities are faring throughout the United States. The issue of inclusion remains UCP's primary focus, but a more person-centered approach creates a better understanding of how it is defined. While it is a step in the right direction to close large State institutions that isolate individuals from the rest of their community and allow individuals a meaningful choice to live more independently in their own home or apartment or in small home-like settings, true inclusion means so much more:

- **Are individuals still isolated at their non-institutional home? Are they happy or lonely? Do they have meaningful relationships and friends?**
- **Are individuals stuck in their residence, or do they regularly go out into the community and have an active and social presence in their neighborhoods?**
- **Are individuals getting healthier, since good health is key to a high quality of life?**
- **Are the families of individuals with disabilities healthy and functional? Are they receiving support in the community?**

To better answer these questions about the true quality of life for Americans with intellectual and developmental disabilities and their families, substantial revisions were made to the *Case for Inclusion* index. A critical part of these changes was to emphasize the importance of the National Core Indicators (NCI), a survey that uses in-person interviews and extensive questioning to better reflect the true health, safety and quality of life of individuals, with 39 States participating and 19 States publicly reporting their survey results in 2014.

For the 2015 index, 42 States participated in NCI and 29 States reported their person-centered survey results for a much more national perspective and comparison. That makes this year's ranking the most comprehensive look at person and family centered outcomes in those 29 States since UCP first started the *Case for Inclusion* in 2006.

UCP made several major enhancements to the 2014 Case for Inclusion report to take a closer look at how Americans with intellectual and developmental disabilities are faring throughout the United States.

In the past, UCP's *Case for Inclusion* scored States on whether or not they participated in the NCI survey. Beginning in 2014, UCP used nine different NCI data measures from the survey, to paint a more complete picture of the quality of life and inclusion for individuals. In addition, UCP began ranking States on whether or not they participate in the NCI's child survey, as part of the Keeping Families Together section of the *Case for Inclusion* ranking. In total, NCI-related data measures now make up 18 points of the 100-point *Case for Inclusion* scale, up from six points in prior rankings. States not participating and tracking outcomes through NCI see a loss of up to 20 points (States are given two points in Keeping Families Together if they also participate in NCI's Child and Family Survey).

In addition, in 2014 UCP enhanced the Promoting Productivity section of the ranking by including measures on how successful States are at placing individuals in work through vocational rehab, the average number of hours worked and the placement rate of individuals participating in the program after one year.

In summary, in 2014, UCP added 14 new data measures (25 points out of 100), eliminated four measures that were no longer regularly updated or were not changing (15.5 points out of 100) and re-weighted another six measures to keep the full scale consistent at 100 points.

As always, the rankings in this report are a snapshot in time. Most data is from 2013, 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. For example, prior to 2010 Alaska estimated the number of individuals being served in a family home. In 2010, the State reported an exact number that was less than 10 percent of the prior estimate. UCP has also uncovered definitional variances between certain States in what qualifies as "competitive employment," despite widely accepted definitions. When 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.

Category	Measure		2007–2013		2014–2015		2015 Data Source
Promoting Independence	Community-Based	% of Recipients with ID/DD on HCBS	9	50	9	50	RTC
		% of ID/DD Expenditures on HCBS	7		7		RTC
		% of ID/DD Expenditures on Non-ICF-MR	8		8		Coleman
	Residential Services in the Community (includes all types)	1-3 Residents - %	13		13		RTC
		1-6 Residents -%	11		11		RTC
		16+ Residents % (smaller %, higher rank)	-4		-4		RTC
		% in Large State Facilities	-3		-3		RTC
	Waivers Promoting Self-Determination		2				
	NCI - % Self-Directed				2		NCI
Tracking Health, Safety & Quality of Life	Quality Assurance - NCI Participation		6	12	0	14	
	NCI - Recent Dental Visit				2.8		NCI
	NCI - Lonely Less than Half the Time				2.8		NCI
	NCI - Not Scared in Own Home				2.8		NCI
	NCI - Inclusion (sum of 4 measures)				2.8		NCI
	NCI - Relationships Other than Staff and Family				2.8		NCI
	Abuse		6				
Keeping Families Together	Family Support per 100k		6	12	3	8	Coleman
	% in a Family Home		6		3		Coleman
	NCI - Child/Family Survey Participation				2		NCI
Promoting Productivity	Has Medicaid Buy-In Program		2	10	2	12	Mathematica
	Competitive Employment - %		6.5		4.0		ICI
	Voc Rehab - per 100k		1.5				
	Voc Rehab - Rehab Rate (finding a job)				2		ICI
	Voc Rehab - Number of Hours Worked				2		ICI
	Voc Rehab - Retain Job for One Year				2		ICI
Reaching Those in Need	Waiting List - Average % Growth for Residential and HCBS		9	16	9	16	RTC,Kaiser
	Individuals with ID/DD Served per 100k of Population		3		2		RTC
	Ratio of Prevalence to Individuals Served		4		2		Census
	Uses Federal Functional Definition for Eligibility or Broader				3		NASDDDS
			100		100		

CENSUS: U.S. Census Bureau's Annual Community Survey 2010.
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 2013.
KAISER: Kaiser Family Foundation's State Indicators – Waiting Lists for HCBS Waivers 2013.
MATHEMATICA: Mathematica's Enrollment, Employment, and Earnings in thel 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 2013–2014 and Child Family Survey for FY2012–2013 and FY2013–2014.
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 2015 report provided to UCP. The 2014 report is available online.

SIGNIFICANT TAKEAWAYS FROM THE 2015 RANKINGS

PROMOTING INDEPENDENCE

1 **All States still have room for improvement, but some States have consistently remained at the bottom 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. Mississippi and Texas also do not participate in NCI.

2 **32 States, down from 38, 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.

3 **As of 2013, 14 States report having no State institutions to seclude those with ID/DD**, including Alabama, Alaska, Hawaii, Indiana, Maine, Michigan, Minnesota, New Hampshire, New Mexico, Oregon, Rhode Island, Vermont, West Virginia and Washington, D.C. Another 10 States have only one institution each (Arizona, Delaware, Idaho, Montana, Nebraska, Nevada, North Dakota, South Dakota, Utah and Wyoming). Since 1960, 220 of 354 State institutions have been closed (5 more in the past year alone), according to the University of Minnesota's Research and Training Center on Community Living. Another 13 more are projected to close by 2016 in California, Massachusetts, New Jersey(3), New York(2), Oklahoma(2), Tennessee(2) and Virginia(2).

4 **26 States, up from 18, 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 79 percent. Just eight States meet a top-performing 90 percent Home-like Setting Standard: Arizona, California, Colorado, D.C., Hawaii, Nevada, New Hampshire, and Vermont.

5 **Ten States, up from seven last year, report at least 10 percent of individuals using self-directed services**, according to the National Core Indicators survey in 29 States. These States include Arkansas, Connecticut, Florida, Hawaii, Illinois, Indiana, Kansas, Kentucky, Utah and Virginia.

TRACKING HEALTH, SAFETY AND QUALITY OF LIFE

6 **42 States, up from 39 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 29 States, a 50% increase from last year, reported data outcomes in 2014.

KEEPING FAMILIES TOGETHER

7 **Only 14 States 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, South Carolina, South Dakota, Vermont, Wisconsin, and Wyoming. Alabama and Pennsylvania reported that they were providing higher levels of family support in last year's ranking.

PROMOTING PRODUCTIVITY

8 **Just 8 States, down from 10 last year, report having at least 33 percent of individuals with ID/DD working in competitive employment**. These States include Connecticut, Maryland, New Hampshire (newly added), New Mexico, Oklahoma, Vermont, Washington, and West Virginia (newly added). Louisiana, Nebraska, Oregon and Virginia reported that they met this threshold in last year's ranking, but reported a decrease in competitive employment this year.

9 **14 States report successfully placing at least 60 percent of individuals in vocational rehabilitation in jobs**, with fifteen States reporting the average number of hours worked for those individuals placed being at least 25 hours and three States reporting at least half of those served getting a job within one year. Only California met the standard on all three success measures this year compared to last year's ranking, when Nebraska and South Dakota were the only two States to report meeting all three thresholds.

SERVING THOSE IN NEED

10 **Waiting lists for residential and community services are high and show the unmet need**. More than 322,000 people, 5,000 more than last year, are on a waiting list for Home and Community-Based Services. This requires a daunting 44 percent increase in States' HCBS programs. 16 States, a decrease from 22 last year, report no waiting list or a small waiting list (requiring less than 10 percent program growth).

2015 THE CASE FOR INCLUSION RANKINGS

By Ranking

States	2015 Ranking
Arizona	1
Maryland	2
Missouri	3
New York	4
Hawaii	5
Colorado	6
Minnesota	7
Dist. of Columbia	8
South Carolina	9
Ohio	10
Georgia	11
Maine	12
Alabama	13
Massachusetts	14
Utah	15
California	16
Connecticut	17
Oregon	18
Kentucky	19
Kansas	20
Vermont	21
Pennsylvania	22
Indiana	23
Louisiana	24
New Hampshire	25
Washington	26
Florida	27
New Jersey	28
Michigan	29
West Virginia	30
Nevada	31

States	2015 Ranking
Tennessee	32
Wisconsin	33
North Carolina	34
Delaware	35
New Mexico	36
Nebraska	37
South Dakota	38
Rhode Island	39
Alaska	40
Virginia	41
North Dakota	42
Oklahoma	43
Iowa	44
Wyoming	45
Idaho	46
Illinois	47
Montana	48
Arkansas	49
Texas	50
Mississippi	51

2015 THE CASE FOR INCLUSION RANKINGS

Alphabetical

States	2015 Ranking
Alabama	13
Alaska	40
Arizona	1
Arkansas	49
California	16
Colorado	6
Connecticut	17
Delaware	35
Dist. of Columbia	8
Florida	27
Georgia	11
Hawaii	5
Idaho	46
Illinois	47
Indiana	23
Iowa	44
Kansas	20
Kentucky	19
Louisiana	24
Maine	12
Maryland	2
Massachusetts	14
Michigan	29
Minnesota	7
Mississippi	51
Missouri	3
Montana	48
Nebraska	37
Nevada	31
New Hampshire	25
New Jersey	28
New Mexico	36

States	2015 Ranking
New York	4
North Carolina	34
North Dakota	42
Ohio	10
Oklahoma	43
Oregon	18
Pennsylvania	22
Rhode Island	39
South Carolina	9
South Dakota	38
Tennessee	32
Texas	50
Utah	15
Vermont	21
Virginia	41
Washington	26
West Virginia	30
Wisconsin	33
Wyoming	45

SUB-RANKING BY MAJOR CATEGORY

Although the overall ranking presents a comprehensive view of each State and the District of Columbia, it is more 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 might 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	43.5	12	12.1	1	1.5	44	5.4	46	10.5	38	73.0	13
Alaska	43.2	14	0.0	32	1.6	42	6.6	20	10.4	40	61.8	40
Arizona	47.3	2	11.3	21	7.1	1	5.8	41	14.3	5	85.8	1
Arkansas	25.0	50	12.0	2	1.2	48	5.9	40	11.3	28	55.5	49
California	45.1	7	0.0	32	4.5	7	7.6	7	14.9	2	72.2	16
Colorado	44.8	9	11.5	14	1.1	50	7.4	9	11.8	24	76.6	6
Connecticut	38.8	34	11.9	4	3.3	20	8.2	5	9.8	44	72.0	17
Delaware	41.5	26	0.0	32	4.2	13	5.3	47	13.5	8	64.4	35
Dist. of Columbia	42.6	18	11.7	9	2.3	33	4.6	48	13.3	10	74.5	8
Florida	40.9	28	11.6	12	3.0	26	3.3	50	10.2	41	69.0	27
Georgia	44.3	11	11.6	11	1.5	46	7.1	11	9.0	46	73.5	11
Hawaii	46.8	4	10.5	29	3.4	17	2.8	51	13.3	9	76.8	5
Idaho	38.5	36	0.0	32	1.1	51	6.1	34	13.1	12	58.7	46
Illinois	27.8	49	11.5	13	1.7	41	5.8	43	9.7	45	56.5	47
Indiana	37.9	38	11.6	10	2.6	32	6.7	18	11.2	30	70.0	23
Iowa	37.1	41	0.0	32	1.6	43	6.6	22	14.2	6	59.5	44
Kansas	39.2	30	11.1	24	2.0	37	6.5	25	12.5	19	71.3	20
Kentucky	41.2	27	10.8	28	1.2	47	6.3	29	12.2	22	71.7	19
Louisiana	35.4	42	11.0	25	6.4	3	6.2	30	10.7	35	69.8	24
Maine	42.4	19	10.8	27	1.5	45	5.9	37	12.8	17	73.4	12
Maryland	44.8	8	11.3	22	1.2	49	8.3	3	12.4	21	78.0	2
Massachusetts	42.4	20	11.5	16	1.7	40	6.5	23	10.7	34	72.8	14
Michigan	44.7	10	0.0	32	4.0	14	7.0	14	13.2	11	68.8	29
Minnesota	41.8	23	11.5	15	3.3	21	6.9	16	11.2	29	74.6	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
Mississippi	8.4	51	2.6	30	2.1	35	5.6	45	10.5	37	29.2	51
Missouri	42.2	21	11.4	19	4.5	8	7.0	12	12.8	16	77.8	3
Montana	35.1	44	0.0	32	3.4	18	6.0	36	11.4	26	55.9	48
Nebraska	41.7	24	0.0	32	1.9	38	7.0	13	12.5	20	63.1	37
Nevada	45.6	6	0.0	32	3.0	25	6.7	19	10.1	42	65.4	31
New Hampshire	47.0	3	0.0	32	2.7	28	7.2	10	12.8	15	69.7	25
New Jersey	35.4	43	11.9	5	2.6	31	6.2	31	12.9	14	69.0	28
New Mexico	43.2	15	2.4	31	4.5	9	6.2	32	7.5	47	63.8	36
New York	39.2	32	11.4	20	4.3	12	6.4	26	15.5	1	76.8	4
North Carolina	30.3	48	11.8	6	4.4	11	6.5	24	11.8	23	64.9	34
North Dakota	37.3	40	0.0	32	2.2	34	6.6	21	14.3	4	60.4	42
Ohio	39.2	31	11.4	17	5.9	4	6.1	33	11.2	31	73.8	10
Oklahoma	34.6	45	11.4	18	2.0	36	5.9	38	5.6	49	59.5	43
Oregon	45.8	5	0.0	32	4.4	10	7.7	6	14.0	7	72.0	18
Pennsylvania	39.2	33	11.8	7	3.2	22	6.4	28	10.0	43	70.6	22
Rhode Island	43.4	13	0.0	32	2.7	29	5.7	44	10.6	36	62.4	39
South Carolina	38.3	37	11.7	8	6.4	2	6.9	15	10.9	32	74.3	9
South Dakota	37.8	39	0.0	32	3.1	24	7.6	8	14.5	3	63.0	38
Tennessee	42.7	17	12.0	3	1.7	39	4.0	49	4.7	50	65.1	32
Texas	31.6	47	0.0	32	3.3	19	5.8	42	0.8	51	41.5	50
Utah	40.2	29	10.9	26	3.7	16	6.4	27	11.6	25	72.8	15
Vermont	47.3	1	0.0	32	3.8	15	8.6	2	10.9	33	70.6	21
Virginia	33.9	46	11.2	23	2.7	30	5.9	39	7.3	48	61.0	41
Washington	41.8	22	0.0	32	4.6	6	10.1	1	13.0	13	69.5	26
West Virginia	41.7	25	0.0	32	3.1	23	8.3	4	12.6	18	65.7	30
Wisconsin	42.8	16	0.0	32	4.7	5	6.1	35	11.3	27	64.9	33
Wyoming	38.8	35	0.0	32	2.9	27	6.8	17	10.4	39	58.9	45

MOST IMPROVED AND BIGGEST DROPS SINCE 2007

		2015	2007	Difference 07–15
IMPROVED	Dist. of Columbia	8	49	41
	Missouri	3	41	38
	Ohio	10	48	38
	Maryland	2	33	31
	Kentucky	19	40	21
	Utah	15	36	21
	Louisiana	24	44	20
	Alabama	13	32	19
	Georgia	11	30	19
DROPPED	Vermont	21	3	-18
	Michigan	29	9	-20
	Delaware	35	14	-21
	Idaho	46	25	-21
	New Mexico	36	13	-23
	Wyoming	45	17	-28
	Montana	48	19	-29
	Alaska	40	2	-38

MOST IMPROVED STATES

↑41 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 92% of those served are in home-like settings.

↑38 PLACES

Missouri

Dramatically increased the portion of resources dedicated to people in the community (from 59 percent to 86 percent), closed six State institutions, reducing by 57 percent the number of individuals isolated in large State institutions, and started participating in and reporting outcomes for the NCI.

↑38 PLACES

Ohio

Dramatically increased the share of individuals (from 63 percent to 83 percent) and resources (from 50 percent to 64 percent) dedicated to the community, closed a State institution, reduced 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.

↑31 PLACES

Maryland

Substantially increased the portion of resources dedicated to people in the community (from 86 percent to 100 percent), dramatically increased the portion of people served in home-like settings (from 74 percent to 83 percent), closed the last two State institutions, started participating and reporting outcomes for the NCI, and added a Medicaid Buy-In program.

↑21 PLACES

Kentucky

Reports an increase in the share of individuals (from 79 percent to 97 percent) and resources (from 63 percent to 73 percent) dedicated to the community and reduced the population at State institutions by 59 percent. It also added a Medicaid Buy In program to support coverage when individuals work and increase their income.

↑21 PLACES

Utah

Substantially increased the portion of resources dedicated to people in the community (from 64 percent to 83 percent), and started participating and reporting outcomes for the NCI.

↑20 PLACES

Louisiana

Had a huge improvement in the portion of individuals (from 49 percent to 73 percent) and resources (from 41 percent to 54 percent) dedicated to community services, closed six large State institutions and had a significant drop in the portion of individuals served in large institutions (from 18 percent to 2 percent).

↑19 PLACES

Alabama

Closed its only large State institution and reports a significant increase in competitive employment (from 4 percent to 24 percent).

↑19 PLACES

Georgia

Reports a significant increase in the share of individuals (from 88 percent to 95 percent) and resources (from 73 percent to 88 percent) dedicated to the community, closed three large State institutions and reduced the population at State institutions by 75 percent.

STATES WITH THE BIGGEST DROPS

↓38 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 at around 200 people served in a family home. Alaska does not participate in NCI and therefore loses out gaining a better understanding of individuals' true quality of life and inclusion and the related points participating in that survey provides.

↓29 PLACES

Montana

down 29 places: Reported a significant 46 percent reduction in the portion of individuals served in home-like settings (from 80 percent to 44 percent) and does not participate in the NCI.

↓28 PLACES

Wyoming

Primarily due to the fact that it does not participate in NCI. Remained stagnant while most other States improved overall causing the State to fall in comparison to others, and had a drop in competitive employment (from 25 percent to 18 percent).

New Mexico

Primarily due to not reporting on all outcomes measures on the NCI in which it just started participating. Survey data is usually provided in the following year so these outcomes will be available for the 2016 ranking and New Mexico may score much higher as a result.

Delaware

Does not report outcomes from the NCI in which it just started participating. Reported a significant decrease in the rate of competitive employment (from 30 percent to 19 percent).

Idaho

Increased the share of individuals (from 75 percent to 91 percent) but only slightly increased the share of resources (from 51 percent to 59 percent) dedicated to the community. Significantly reduced the portion of individuals served in home-like settings (from 92 percent to 83 percent) and does not participate in the NCI.

Michigan

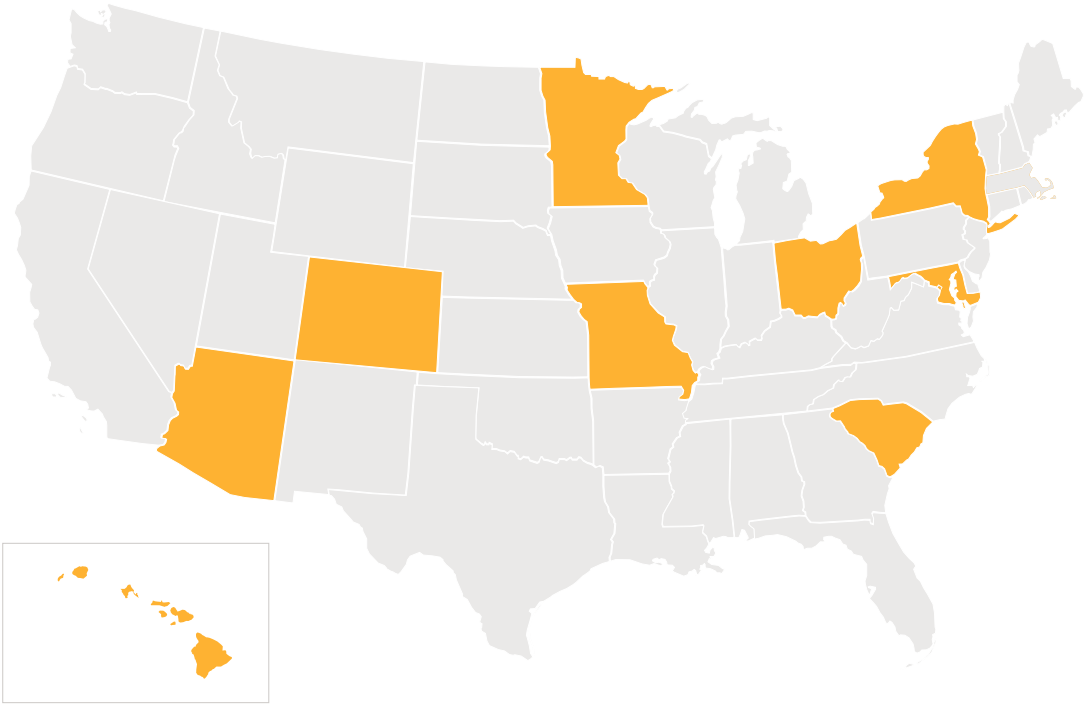
Primarily due to not reporting outcomes from the NCI in which it just started participating. Survey data is usually provided in the following year so these outcomes will be available for the 2016 ranking and Michigan may score much higher as a result.

Vermont

Primarily due to not reporting on outcomes from the NCI in which it just started participating. Survey data is usually provided in the following year so these outcomes will be available for the 2016 ranking and Vermont may score much higher as a result.

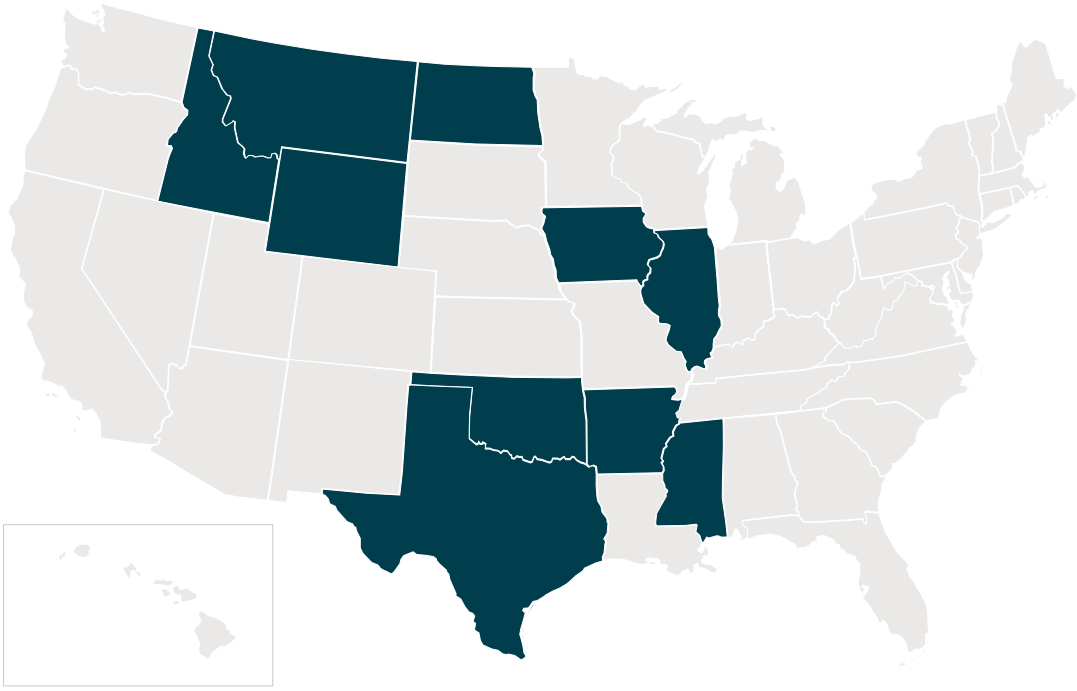
THE BEST, THE WORST AND FACTS ABOUT THE TOP 10

THE BEST PERFORMING STATES



1. Arizona
2. Maryland
3. Missouri
4. New York
5. Hawaii
6. Colorado
7. Minnesota
8. Dist. of Columbia
9. South Carolina
10. Ohio

THE WORST PERFORMING STATES



42. North Dakota
43. Oklahoma
44. Iowa
45. Wyoming
46. Idaho
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 New York (3rd biggest) and Ohio (#7) as well as "small" population States such as Hawaii (#40) 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 (2nd richest), Hawaii (8th richest), and D.C. (9th richest) and less affluent States such as Ohio (#40) and South Carolina (#44).

3. **Top Performers are high tax and low tax burden States**—"high tax burden" States include New York (#1), Minnesota (#6), and Maryland (#7) and "low tax burden" States include Arizona (#35), South Carolina (#42), and Missouri and Colorado (tied for #33).

4. **Top Performers are big and low spenders per person served through the Home and Community-Based Services**—"big spender" States are New York (#11) and D.C. (#3) and "low spender" States include Arizona (#50), Maryland (#44), and South Carolina (#45).

5. **Top Performers are politically diverse**. Seven of the top ten are "Blue States," according to their 2012 Presidential Election results, while three "Red States" were in the top ten.

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 2014 Report (table 4.2).

Transition Case Study

CASE STUDIES: ISSUES OF WAITING LISTS AND TRANSITION

Each year UCP includes case studies in the Case for Inclusion to highlight policy or practice trends that are impacting Americans with intellectual and developmental disabilities. This year's report highlights two case studies: **1. How States that are being transparent with and managing their waiting list** (as well as strategies and model legislation to make your State's waiting list transparent and, ultimately, smaller) and **2. The latest evidence-based strategies to help young people successfully transition into an enriched adulthood** complete with work, postsecondary education and a full quality of life.

WAIT NO MORE:

A DETAILED STRATEGY TO ELIMINATE YOUR STATE'S WAITING LIST

Ever since UCP started its groundbreaking *Case for Inclusion* ranking in 2006, each State's waiting list is the area that gets the most attention by advocates and family members. Recently, one family member inquired about which States do not have any waiting lists because she is thinking about moving her family to another State to get better services for her son. Reactions like this to the *Case for Inclusion* waiting list data are common.

Some States have done better than others over the past decade in reducing or eliminating waiting lists. Regardless of size, waiting lists remain frustrating and elusive to many advocates. Battles for additional funding to "buy down the waiting list" (which makes it sound as if policymakers are negotiating a discount rather than bettering people's lives) are perennial in State legislatures.

As part of this year's *Case for Inclusion*, UCP wanted to empower advocates, family members and policymakers with greater insight into how States manage waiting lists and to advance a legislative public policy strategy to provide a path to ultimately reduce and then eliminate waiting lists.

This case study seeks to do just that: learn from how various States manage and publicize their waiting lists and then combine these lessons with a comprehensive and multi-year legislative strategy to end a waiting list.

1	2	3
Transparency	Personalization & Prioritization	Persistence

UCP wanted to empower advocates, family members and policymakers with greater insight into how States manage waiting lists and to advance a legislative public policy strategy.

1. TRANSPARENCY

Knowledge is power but withholding knowledge is even more power.

In many State Medicaid programs serving those with intellectual and developmental disabilities, this truism is not just known but it is a preferred business practice. When a State does not maintain a waiting list or maintains one with minimal or outdated information, that withheld knowledge means that advocates do not have the tools to adequately define the scope of the need and family members waiting have no sense of context of when their need may be addressed. In addition, legislatures do not necessarily have all the information that enables them to make sound, evidenced-based legislative decisions.

It doesn't have to be this way. In many States it is not. In all States it should not.

But what should be done. Some States—even those with large waiting lists—are leading the way in how that waiting list is publicly maintained and what information is provided. Alaska is a State that maintains a large waiting list, in comparison to the size of its program. But it does so with a high degree of transparency. That is not an accident. The Alaska statute is very explicit about which seven detailed areas the State must annually report to the legislature and the public:

1. Purpose of waiting list (including individual's rights);
2. Process, ranking criteria and management of waiting list;
3. Basic demographic information—age, sex, racial and ethnic background by region;
4. Level of need and services and supports required;
5. Individuals removed from the waiting list during the past year by number and reason and length of wait;
6. Number of individuals waiting more than 90 days; and
7. Annual data from the Department of Education about students with ID/DD including those graduating, those dropping out, and those turning 22 years old without graduating.

The Alaska waiting list is now called the Registry, implying it is the first step to getting services rather than a forgotten wasteland where a person may be kept waiting indefinitely.

Looking at the 2013 report compared to the 2006 one, one learns that:

- **The number of people on the waiting list has dropped to 613 in 2013 from 1006 in 2006, a drop of 39%.**
- **The number of kids on the waiting list (those under 22 years old) has dropped to 431 in 2013 from 818 in 2006, a drop of 47%.**
- **Most of those on the waiting lists are under 22 (70%).**
- **The average wait time for someone on the waiting list is 41 months (about the same as it was in 2006 at 38 months).**
- **It would require $23 million in State Medicaid funding to meet the annual need for the waiting list, and these taxpayer costs are broken out in detail by type of service and number of people needing that service.**
- **In 2013, 363 people moved off the waiting list (59% of the total waiting) during the year, showing how dynamic the Registry is. Most of those (209 or 34%) were moved off the waiting list because they received services. Those individuals spent an average of 25 months on the Registry. Another 119 were unresponsive to information requests to update their status.**

The report further breaks down the waiting list by region, gender, and age in much more detail.

This compares to another State such as Utah. Utah publishes an extensive annual report (2012 edition) of services provided by its Division of Services for People with Disabilities. That report has some detailed service information and a fair amount of historical data. However, its waiting list data consists of one page with six charts and no detail, unlike that provided by the State of Alaska. That is, in part, because the Utah Division decides what data and level of detail will be provided, and that can vary from year to year. That lack of transparency in one place means that advocates and family members do not readily have the tools to understand the need on the waiting list and then advocate for funding or prioritization of those needs. In its defense, the State of Utah does host extensive dashboards of services provided and of people waiting by service. But this information is still not as comprehensive on those waiting as that provided by Alaska. But despite Utah's lack of transparency, it is still more comprehensive than what Minnesota provides. Its annual waiting list report is simply a list of the number of individuals waiting by county, with no further detail.

To have full transparency, advocates should work with State legislators to have the following waiting list model legislation, built off the Alaska statute, passed into law in their State:

MODEL LEGISLATION

An Act to Create a Transparent Waiting List for Those with Intellectual and Developmental Disabilities in Need

[To amend State statute delineating the duties of the Department serving those with intellectual and developmental disabilities]

When State funding is not adequate to meet service needs, the department shall establish a waiting list, to be called the registry, for persons with developmental disabilities who would be eligible to receive State-funded services under [reference relevant statute] if adequate State funding were available. The department shall, on an annual basis, review the waiting list and submit a report to the governor containing the information required under this subsection. The department shall send a copy of the report to the persons chairing the House and Senate finance committees and the persons chairing the House and Senate health, education and social services committees and shall notify the full legislature that the report is available to all legislators. The report must:

1. Describe the purpose for the waiting list and the strategies used to notify persons about the waiting list, and must include a copy of the information used by the department to inform individuals and families about their rights and responsibilities under [relevant section of State law];
2. Explain how an individual is placed on the waiting list, what criteria determine rank on the list, with at least quarterly updates to such assessments, and how the waiting list is used to select individuals equitably and fairly across the State;
3. Give the basic demographic information across all regions about the age (under 22 years old, from 23 to 39 years old, from 40 to 59 years old and more than 59 years old), gender, and racial and ethnic background of the individuals on the waiting list;
4. Identify the level of need and preferences of the individuals and families on the waiting list for the services and the supports that may be necessary to meet their needs and project an annual cost to meet this need and show these costs by age and length of time the individual has remained on the waiting list;
5. Identify how many individuals were removed from the waiting list during the 12 months covered by the report, why they were removed from the list, and how long the individuals had been waiting for services or supports before they were removed from the list, shown by age;
6. List the number of individuals who have been on the waiting list for 6 months, 12 months, 24 months, 36 months, 48 months, or more by age and with an account of the department's steps to regularly review each individual's status while waiting for services or supports;
7. Report annual data from the [education department] about the number of students in special education with developmental disabilities graduating from high school, dropping out of high school before reaching age 22, or reaching age 22 without graduating from high school.

2. PERSONALIZATION AND PRIORITIZATION

Transparency gives advocates a complete picture of those on the waiting list. However, the challenge with advocates mobilizing in support of prioritizing services for those on the waiting list is that the State solely maintains that list and the contact information of those on it. That greatly limits the ability to easily educate the family members and those on the waiting list. Without this, the ability to influence the department, the governor's budget staff and legislators is greatly diminished.

UCP affiliates have shown how informed individuals, advocates and family members can accomplish great things. The same would be true of those on the waiting list. But more than that, those on the waiting list need to access the same accountability structure that those actually receiving HCBS services have. That is why States should be required to refer all those individuals approved for the waiting list to the Protection and Advocacy Systems that ensure the legal rights of those receiving services are respected. In addition, the primary care physician for the medical services that Medicaid is funding should be informed of the fact that his or her patient is on the waiting list and of that patient's rank on the list. This will ensure that if the physician has information that may affect the State's determination of the patient's rank on the list, then the physician is aware and can follow-up with the State to provide more information and context.

It is vital to humanize and personalize those on the waiting list. The perennial fight for additional funding for those on the waiting list is made so much more difficult when the media and advocates are limited in finding real people languishing. But the physicians and Protection and Advocacy Systems, receiving permission from those waiting individuals and working with their family members, can tell their stories in the media and mobilize them to testify before the legislature and to contact policymakers in support of prioritized services and funding. That personalization and prioritization is vital in any public policy reform strategy. The challenge is for advocates to be able to rise above the noise of other pressing public policy issues facing the governor and lawmakers. The best way to do that is to put a face – or dozens of faces – on the situation. The best faces are those who are in the greatest need and who have been waiting the longest.

In 2007, UCP published the Plan for Inclusion, a detailed strategy on how to advance public policy reforms in your State that improve the lives and services for those with intellectual and developmental disabilities. This Plan includes detailed strategies and tactics that allow advocates to personalize and prioritize the people that would be helped with additional funding to reduce the waiting list.

3. PERSISTENCE

Now with the information to understand the waiting list (Transparency) and the structure to Personalize and Prioritize, the last step is Persistence. Public change and additional funding to reduce the waiting list does not happen overnight. Medicaid was first established in 1965, fifty years ago. Waiting lists have been an issue for a long time. However, as with so many initiatives, it requires persistence and sustained effort over many years to accomplish something as important and monumental as reducing and eventually eliminating the waiting list.

There are several complimentary public policy approaches to reducing the waiting list:

- Partner with the Department on a de-institutionalization initiative and use any fiscal savings to reduce the waiting list.
- Pass budget language or a law that any Department surplus funds or lapse balance at the end of the fiscal year be automatically redirected into reducing the waiting list in the subsequent year.
- Build long-term relationships with legislators in both chambers and of both parties to announce and champion a multi-year strategy to reduce the waiting list (many policymakers are looking for a cause and this is a non-partisan one).
- Host a Wait No More Day at the legislature or off-session legislative visits with waiting list families to personalize those waiting for services.
- Share your successful strategies and tactics with UCP so that together we may replicate your success and, in turn, use these approaches to successfully reduce waiting lists in other States.
- Celebrate each small victory or incremental progress (rarely in politics does big change happen all at once. It is often the sum of several incremental steps that together is monumental or transformative over a four or five year period).

Most of all do not be discouraged. This is noble important work. It is best done by those passionate about those impacted. Public policy change is always accomplished by a vocal, effective small group of people. You can play an important role. This case study gives you the background and strategy to advance a major change in your State through a series of small, doable but strategic steps.

TRANSITIONS

THE PROVEN PARENTING AND PROGRAMS TO HELP KIDS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES BECOME HAPPY, PRODUCTIVE, ENGAGED ADULTS

Life is hard. Change is harder. Everyone struggles with transitions in life. Young adults with developmental disabilities are no different.

And yet, they are. The consequences of bad transitions can be greater and longer-term for those with developmental disabilities, even compared to those with other types of disabilities or challenges.

> "Youth with intellectual disabilities are more likely than youth with learning disabilities or emotional/behavioral disorders to stay in school until they age out of eligibility for special education services at age 21 and much less likely than almost all other youth with disabilities to earn a regular high school diploma.
>
> Individuals with intellectual disabilities typically require lifelong support and are often at risk of being excluded from participation in society.
>
> Indeed, most recent reports of the post-school outcomes of youth with intellectual disabilities have found that these youth are less likely than youth with other disabilities to attend postsecondary education, work, live independently, or see friends at least weekly in the early years after leaving high school [emphasis added].[i]"

And they are more reliant on others to aid in (or undermine) this process.

Given all this, as part of this year's *Case for Inclusion*, UCP wanted to dive deeper into the latest research and best practices on transitions. The goals are two-fold:

1. To inform advocates and policymakers of key programming that support better transitions for young adults with developmental disabilities.
2. To empower parents, family members and young adults with developmental disabilities themselves of how to best support the transition from young adult to an adult with a full, inclusive and productive life.

UCP wanted to empower advocates, family members and policymakers with greater insight into how States manage waiting lists and to advance a legislative public policy strategy.

There are many recent and in-depth reports on transitions. This case study will summarize major findings.

How does one define or measure a successful transition? One must have specific, measureable outcomes that approximate a host of softer, less measureable but desired outcomes – happiness, feelings of self-worth and a sense of a meaningful life – that signify a successful transition.

In 2005 and 2006, UCP struggled with a similar concept with how to measure inclusion as we were putting together the first *Case for Inclusion* ranking. We grouped key measurable outcomes that would signal an inclusive life – living in the community in as home-like setting as possible (as opposed to being isolated in a large institution), participating in work, and not languishing on a waiting list. In 2014, we expanded that list of outcomes to infuse person-level (and self-reported) feelings and behaviors that would be key indicators of an inclusive life

– self-directing services and providers, regularly going into the community (church, errands, for entertainment, and for dining), having (non-staff) friends, not feeling lonely, feeling safe, and receiving health care.

The transitions research takes a similar approach.

To best measure a successful transition, researchers used a national longitudinal survey of parents, youth, teachers and school officials called the National Longitudinal Transition Study-2 (NLTS2) which ran from 2000 to 2009 (for those ages 13 to 16 at the start of the study) to chart four key outcomes to best measure a successful transition within four years after high school for 490 youth[ii]:

Positive Outcome	Details	Percent Reporting within 2–4 Years after High School
1 Employment	In any job, for any number of hours	41%
2 Postsecondary Education	Enrolled after high school training	35%
3 Enjoyment of Life	Answering "a lot" or "most" of the time to a survey question about how often the individual enjoys life	74%
4 Social Interactions	Answering at least weekly to a survey question about how often the individual gets together with friends outside of organized activities or groups	72%

So if those are the outcomes one wants for youth to have through a successful transition. What does it take to accomplish them? Using regression analysis, researchers identified key characteristics (demographic and family involvement) and best practices (formal school transition program activities) that had the strongest impact on a student having success in all four transition outcome areas. Even more interesting, was the extent of that impact.

Key Family Characteristics for a Successful Transition within Two to Four Years[iii]

Positive Outcome	Characteristic	Impact
1 Employment	Parent expects employment	32x more likely to be employed
	High family income	7x more likely to be employed
	Completed high school	6x more likely to be employed
	High functional academics	3x more likely to be employed
2 Postsecondary Education	Parent expects employment	4x more likely to be enrolled
	High functional academics	4x more likely to be enrolled
	Parent expects postsecondary education	3x more likely to be enrolled
	Medium family income	2x more likely to be enrolled
3 Enjoyment of Life	Parent expects employment	6x more likely to enjoy life
4 Social Interactions	Completed high school	12x more likely to be social

From this, it is clear that families have a tremendous impact on the successful transition of their children into a full and rich adulthood. Most importantly, parents must:

1. **Expect employment for their child**
   85% of parents said they did
2. **Expect postsecondary education for their child**
   Only 38% of parents said they did
3. **Ensure high functional academic skills are realized by their child**
   Only 45% of students reported high functional skills in four key areas
4. **Ensure their child completes high school**
   81% of students did

And while having a medium to high family income helps with a successful transition to employment and postsecondary education, it is not the most important characteristic and clearly this is not something families can easily change. The other four strategies for parents listed above can be accomplished regardless of income and, often, regardless of location (urban or rural). That's exciting and provides a clear, focused roadmap of how parents can lead their child into a successful transition and, ultimately, a full adult life.

Now, what about the student. What programming should the student receive that will equip him or her to transition successfully into adulthood? This same research asked that question and look at the key programming that aided in that transition.

Most Impactful Programs for a Successful Transition within Two to Four Years[iv]

Positive Outcome	Best Practice	Impact
1 Employment	Received work experiences	5x more likely to be employed
	Received youth involvement	5x more likely to be employed
2 Postsecondary Education	Received family involvement	41x more likely to be enrolled
	Received life skills instruction	9x more likely to be enrolled
	Received youth involvement	2x more likely to be enrolled
3 Enjoyment of Life	Received interagency involvement	12x more likely to enjoy life
	Received family involvement	6x more likely to enjoy life
4 Social Interactions	Received interagency involvement	2x more likely to be social

Just like with parents, from this program list we can see the profound impact that particular services have on youth successfully transitioning. While this in no way is to suggest that other services are not important or helpful, this list clearly outlines those services most proven to help youth become complete adults. Sadly, some of these program services are not common. That means that a majority of students are not getting what they need to be successful.

In particular, those individuals who had the following programming outcomes enjoyed the best transition outcomes:

1 Received work experiences
- As evidenced by percent of school day in work experiences
- Only 57% reported having work experiences

2 Received youth involvement
- As evidenced by their involvement in transition planning
- Only 58% reported involving youth

3 Had family involvement
- As evidenced by family involvement in transition planning
- 68% of families reported being involved

4 Had life skills instruction
- As evidenced by student receiving life skills or social skills instruction
- 72% reported receiving this

5 Enjoyed interagency involvement
- As evidenced by an adult service agency representative at the transition planning
- Only 43% reported having this involvement

If these are the five program outcomes that position students for a solid transition, then what are the best practices in these programs? Other research[v] answers this with the curriculum and teaching methods that best produce the desired experience or outcome.

Positive Outcome	Best Practice
Functional Life Skills	Backward chaining
	Forward chaining
	Least-to-most prompting
	Most-to-least prompting
	Progressive time delay
	Response prompting
	Simultaneous prompting
Work Experiences	Computer-assisted instruction
	Community-based instruction
	Constant time delay
	Least to most prompting
	Mnemonics
Youth Involvement (through student involvement in the IEP meeting)	Check and Connect
	Computer-assisted instruction
	Published curricula
	Self-advocacy strategy
	Self-directed IEP
	"Whose Future Is It Anyway" program
Family Involvement	Training modules
Life Skills	Response prompting
	Simulations
	Total task chaining
Interagency Involvement	None identified

Transitions are tough. But with the right parent expectations and evidence-based programming for their students, youth with developmental disabilities can have a solid transition to an adult life rich with work, education, experiences and relationships.

Sadly, we do not have State-level data on what portion of students have achieved the employment, education and quality of life outcomes indicative of a successful transition. That means, at this time, we cannot rank States based on how well they accomplish this.

The purpose of this case study is to be a starting point and to create a basic roadmap for parents and advocates of how they can help their student achieve a solid transition to adulthood. As UCP adapts and expands the *Case for Inclusion* in future years, we will look for survey and State-level outcome data that can successfully paint a better picture of how well States are facilitating transition and rank them accordingly.

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[i] Papay, Clare K, Ph.D. and Linda M. Bambara, Ed.D. "Best Practices in Transition to Adult Life for Youth With Intellectual Disabilities." Hammill Institute on Disabilities. Page 137. Available at: http://cde.sagepub.com/content/37/3/136.full.pdf+html

[ii] IBID. page 138.

[iii] IBID. page 143.

[iv] IBID. page 143.

[v] Test, David, Catherine Fowler, and Paula Kohler. "Evidence-Based Practices and Predictors in Secondary Transition: What We Know and What We Still Need to Know." National Secondary Transition Technical Assistance Center. Revised October 2012. Available at: http://www.nsttac.org/sites/default/files/assets/pdf/pdf/ebps/ExecsummaryPPs.pdf

HOW TO USE & 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?
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, 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 and States need 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. The States 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.

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

In general, 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. All other States were apportioned accordingly based on their outcome between the top- and worst-performing.

As noted, most data is from 2013, 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 2014 or later would not have an impact on the data.

When reviewing an individual State's ranking, it is important to consider action taken since 2013, if any, to accurately understand both where that State was and where it is presently. Also, 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 56 points separate the top performing State from the poorest performing State, 12 points separate the top 10 States, 16 points separate the top 25 States and only 10 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.

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 2015 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. This was the case for one or more RTC data elements used for Delaware, Florida, Georgia, Idaho, Kansas, Kentucky, Maryland, Michigan, Mississippi, New Jersey, New Mexico, North Dakota, Oklahoma, Rhode Island, Texas, Virginia and Wyoming.

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Human Service Transportation Delivery
Non-Emergency Medical Transportation

Office of Transportation Delivery
Kentucky Transportation Cabinet

Vickie Bourne, Executive Director

September 24, 2015

Kentucky
UNBRIDLED SPIRIT™

Medicaid Transportation

Non-emergency medical transportation is for Medicaid members who do not have access to free transportation that suits their medical needs and need to be transported to a Medicaid-covered service. **Coordinated through the Department for Medicaid Services and the Transportation Cabinet and NOT under Managed Care Organizations.**

Kentucky
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Before Coordination

- Non-Emergency Medical Transportation Voucher System
  - Understaffed State case workers in each county issued voucher for Transportation
  - Dept of Medicaid had Thousands of Contracts
  - Delay in Payments to Providers

Kentucky
UNBRIDLED SPIRIT

Before Coordination

- Fraud & Abuse of Non-Emergency Medicaid Transportation
  - Billings for excessive mileage
  - Ineligible trips
  - No Recipient nor Provider Accountability
- Escalating Costs
- No Safety Standards
- Resource Inefficiency
  - Administrative
  - Operational
- Need for Greater Mobility

KY Human Service Transportation Delivery (HSTD)

- Kentucky General Assembly
  Authorizes Program
  - Established Geographical HSTD Regions
  - Determines Transportation as
    lead to administer HSTD Programs
  - Authorized Under existing
    Transportation Laws & Regulations

Kentucky
UNBRIDLED SPIRIT

How the Dollars Flow

Agreements

- Annual Agreements between Partners/Transportation Cabinet
- Transportation Cabinet with Finance Cabinet
  - Annual Agreements with Transportation Broker
- Transportation Broker
  - Agreement Subcontractor

Kentucky
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Who is Eligible to Receive Transportation?

- Must be a KY Medicaid Recipient
- Traveling to or from a Medicaid covered service (excluding pharmacy services)
- The medical service is determined to be medically necessary
- Free transportation which is appropriate for the recipient's medical needs is not available or use of an appropriate and operational household vehicle is not available

Kentucky
UNBRIDLED SPIRIT

Vehicle in the Household Exceptions

- Medical Statement
  - valid for 6 months and can be renewed
- Work/School Statement
  - Valid for 3 months and can be renewed
- Mechanic Statement
  - Valid for 30 days; may submit up to 3 per year
- Officially Cancel or Junk the Vehicle at the County Clerk's Office

Kentucky
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Non-Emergency Medical Transportation

- Hours of Operation

  - Reservation Line is available Monday – Friday from 8:00am – 4:30pm; and on Saturday 8:00am-1:00pm.

  - Transportation Services are provided Monday – Friday from 6:00am – 8:00pm; and on Saturday 8:00am-1:00pm.

  - Services are closed on New Year's Day, Memorial Day, July 4th, Labor Day, Thanksgiving Day, and Christmas Day.

Kentucky
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Non-Emergency Medical Transportation

- 72 Hour Notice Required
- Urgent Care Transportation
- Medical Service Area
- Closest Available Medical Facility

Kentucky
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Broker Responsibilities

- Serve as Gatekeepers
  - Verifying the recipient's eligibility
  - Assessing the recipient's need
  - Educating the recipients
  - Determining the appropriate transportation
    - 02 Regular Taxi Service (Ambulatory)
    - 03 Fixed Route Bus System
    - 04 Non-profit demand response bus service
    - 07 Ambulatory but disoriented
    - 08 Non-ambulatory who needs physical assistance

Kentucky UNBRIDLED SPIRIT

Broker Responsibilities

- Serve as Monitors
  - Vehicle maintenance, inspection and operation
  - Driver qualifications and training, drug and alcohol Testing
  - Complaint tracking, courteous, safe and timely services

Kentucky
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KY Human Service Transportation Delivery

Customer Satisfaction

- 1-800 Line (State & Regional Level)
- Complaint Tracking (State & Regional Level)
- 3.4 Million Medicaid Trips (SFY15)
- Monthly Phone Surveys
  - 98% Customer Satisfaction (July 2015)
- Rider Survey (SFY 15)
  - 98% Customer Satisfaction

Kentucky
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Kentucky – A National Model

" If 10 of the 50 states were to implement a program such as that being created in Kentucky, annual benefits to the Medicaid Program could reach 100 million per year."

Transit Cooperative Research Program Report #91

Kentucky
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KY Human Service Transportation Delivery

Kentucky Transportation Cabinet

Office of Transportation Delivery (OTD)

Recipient Complaint Line

1-888-941-RIDE (7433)

Fax - 502-564-2058

OTD Website:

http://transportation.ky.gov/Transportation-Delivery/Pages/default.aspx

Kentucky
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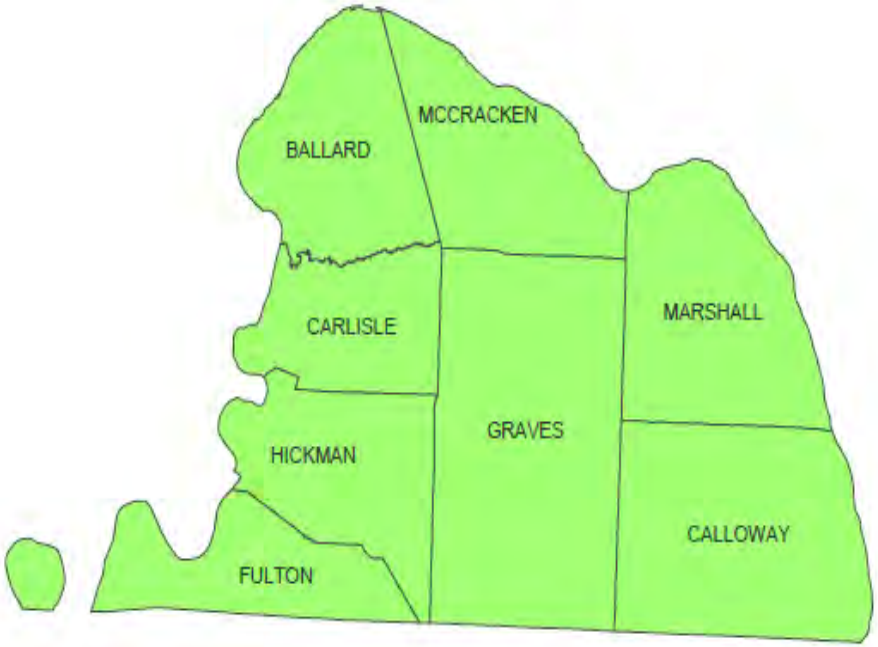
HUMAN SERVICE TRANSPORTATION REGIONS

Kentucky
UNBRIDLED SPIRIT

Region 1

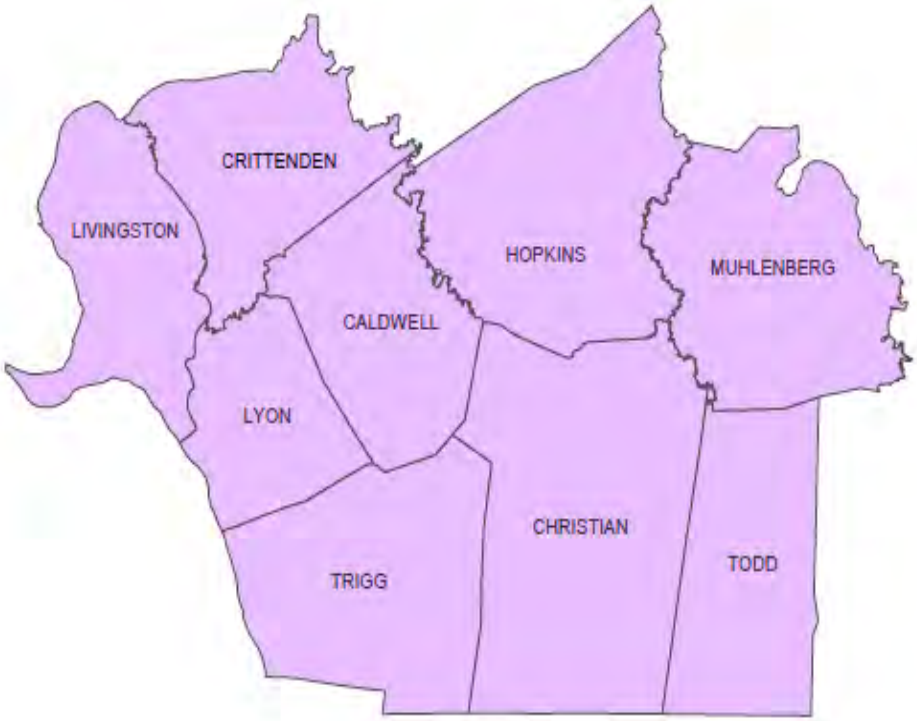
Audubon Area Community Services – AACS
1-844-575-9676



Kentucky
UNBRIDLED SPIRIT

Region 2

Pennyrile Allied Community Services - PACS
1-800-467-4601



Kentucky
UNBRIDLED SPIRIT

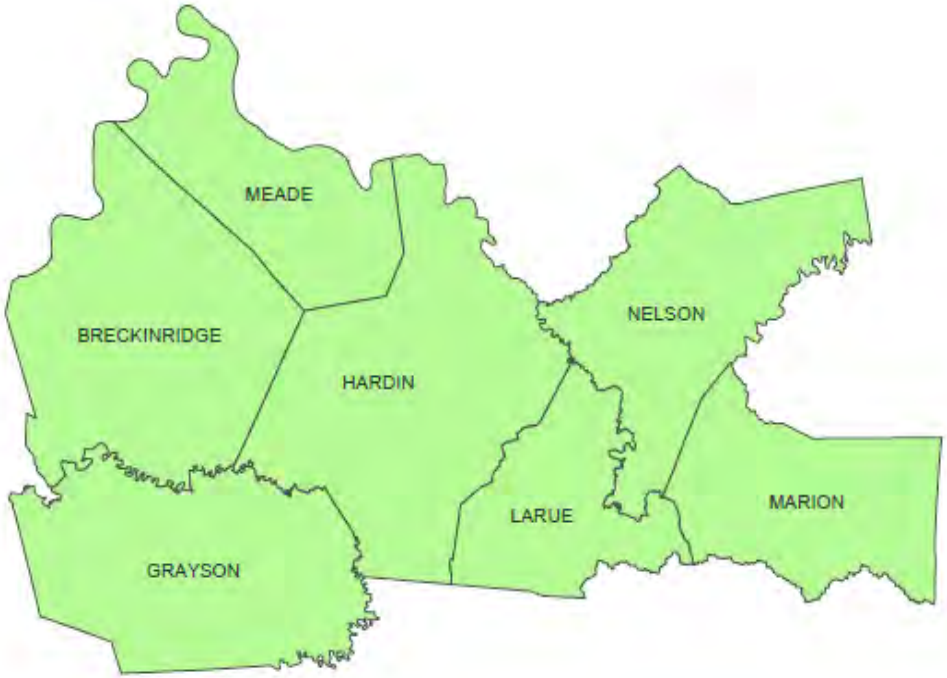
Region 3

Audubon Area Community Services - AACS
1-800-816-3511

Kentucky
UNBRIDLED SPIRIT

Region 4

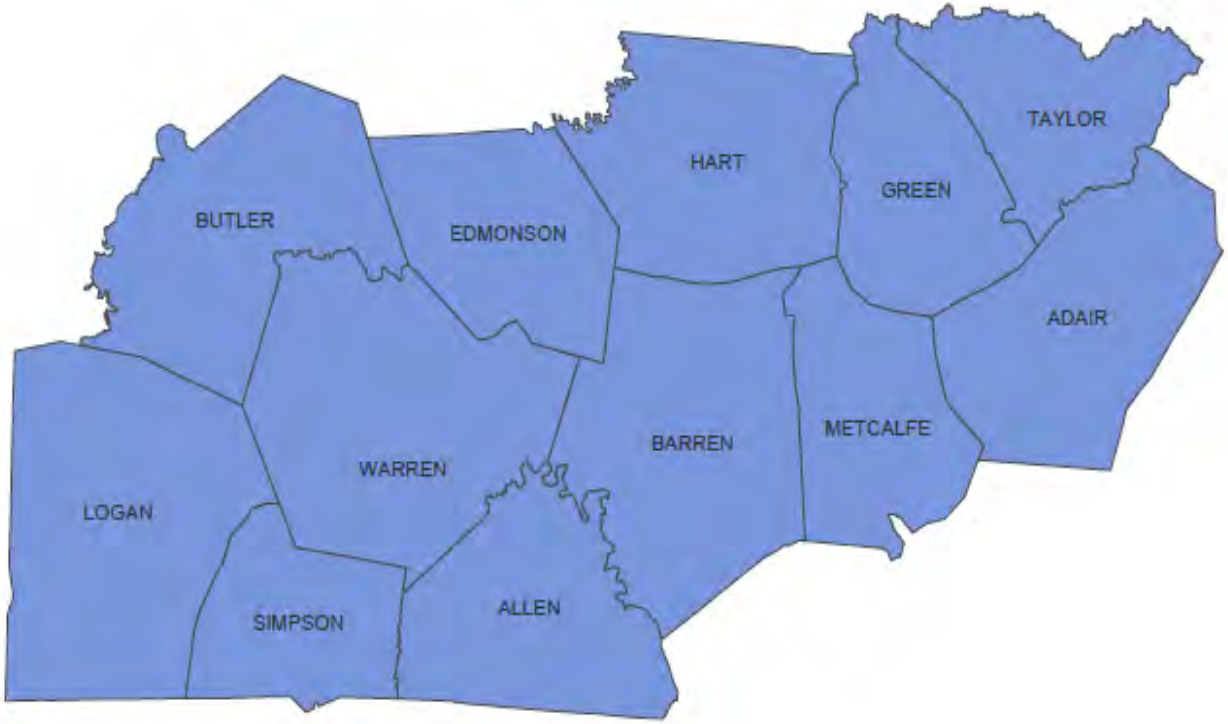
LKLP Community Action Council - LKLP
1-800-245-2826



Kentucky
UNBRIDLED SPIRIT

Region 5

LKLP Community Action Council - LKLP
1-800-245-2826



Kentucky
UNBRIDLED SPIRIT

Region 6

Federated Transportation Services of the Bluegrass
FTSB
1-888-848-0989

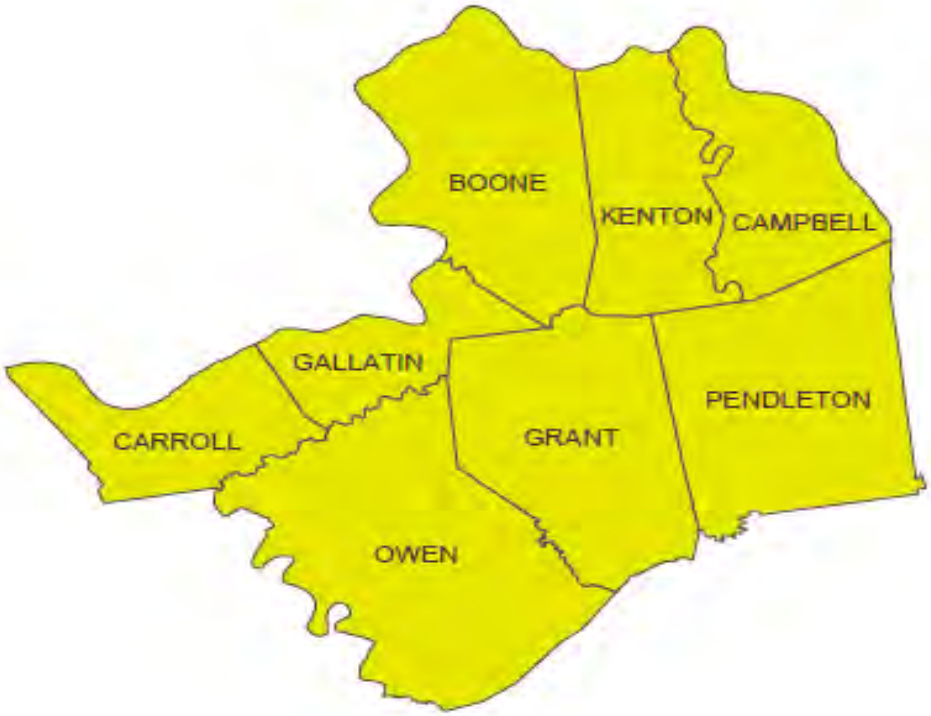
Kentucky
UNBRIDLED SPIRIT

Region 8

Bluegrass Community Action Partnership - BGCAP
1-800-456-6588

Region 9

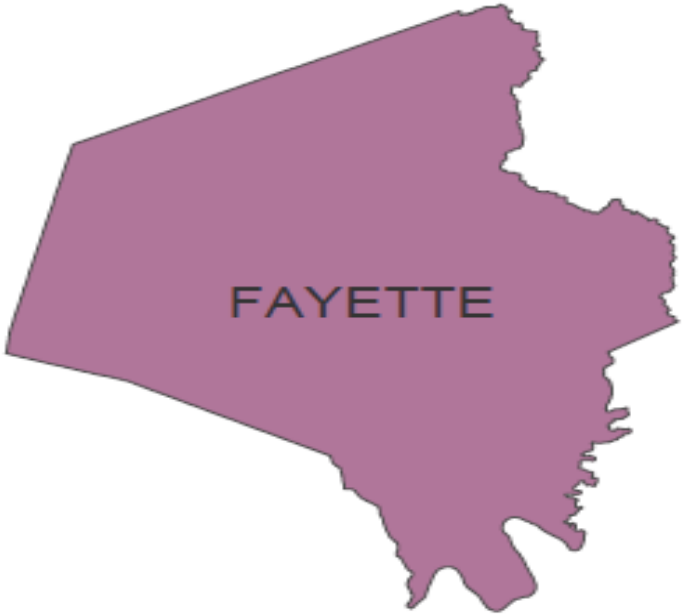
LKLP Community Action Council - LKLP
1-800-245-2826



Kentucky
UNBRIDLED SPIRIT

Region 10

Federated Transportation Services of the Bluegrass
FTSB
1-800-848-0989



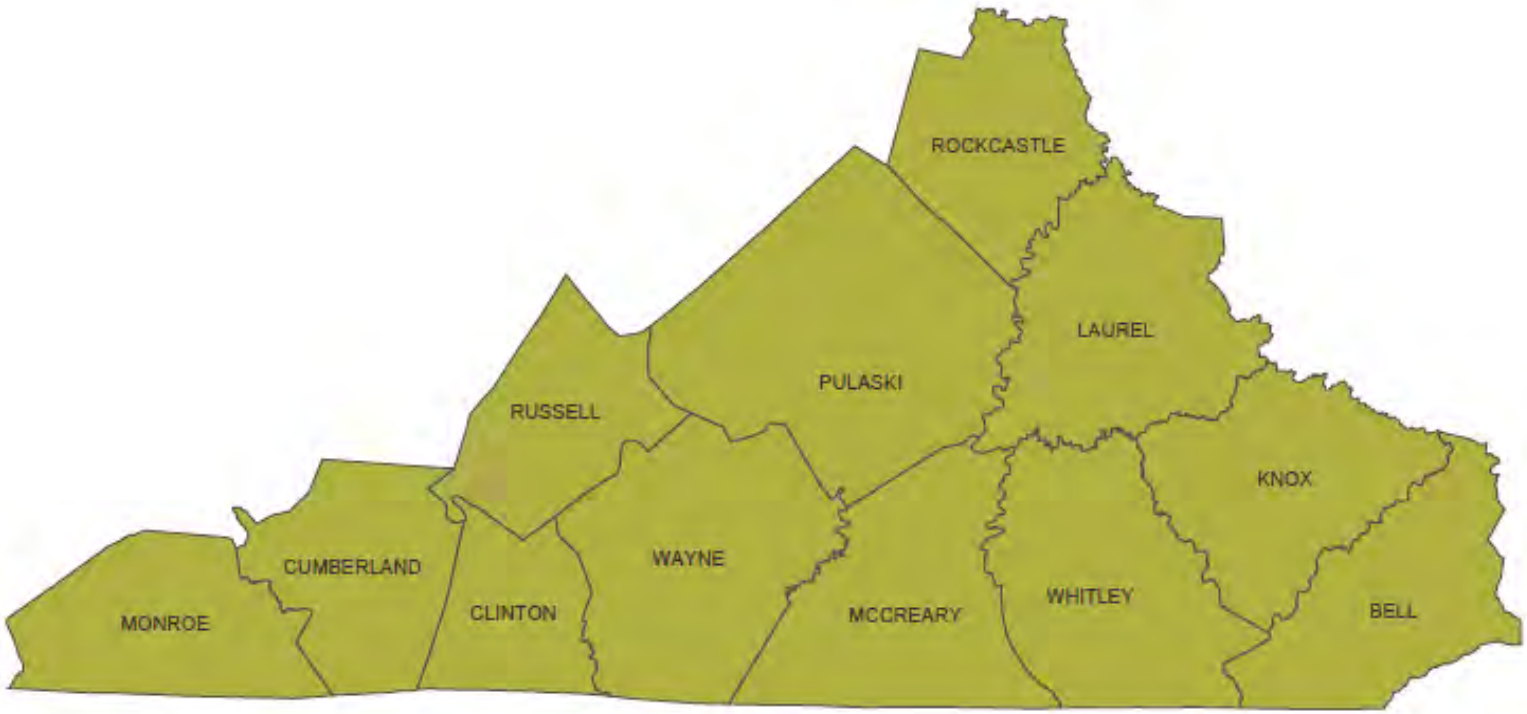
Region 11

Federated Transportation Services of the Bluegrass
FTSB
1-800-848-0989

Kentucky
UNBRIDLED SPIRIT

Region 12

Rural Transit Enterprises Coordinated - RTEC
1-800-321-7832



Kentucky
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Region 13

LKLP Community Action Council – LKLP
1-800-245-2826

Kentucky
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Region 14

Sandy Valley Transportation Services - SVTS
1-800-444-7433

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Region 15

LKLP Community Action Council – LKLP
1-800-245-2826

Kentucky
UNBRIDLED SPIRIT

Region 16

Licking Valley Community Action Program - LVCAP
1-800-803-1310