



**LEGISLATION AND PUBLIC POLICY COMMITTEE (LPPC)
MEETING NOTICE/AGENDA**

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**THE PUBLIC MAY LISTEN IN BY CALLING:
PARTICIPANT CODE:**

**1-800-839-9416
8610332**

DATE: August 25, 2015

TIME: 10:00 a.m. to 3:00 p.m.

LOCATION: State Council on Developmental Disabilities
1507 21st Street, Suite 210
Sacramento, CA 95811
(916) 322-8481

TELECONFERENCE SITE:

Silicon Valley-Monterey Office
2580 North First Street, Suite 240
San Jose, CA 95131
(408) 324-2106

Pursuant to Government Code Sections 11123.1 and 11125(f), individuals with disabilities who require accessible alternative formats of the agenda and related meeting materials and/or auxiliary aids/services to participate in the meeting, should contact Michael Brett at 916/322-8481 or michael.brett@scdd.ca.gov. Requests must be received by 5:00 pm on June 17, 2015.

AGENDA

PAGE

- | | |
|---------------------|----------|
| 1. CALL TO ORDER | J. Lewis |
| 2. ESTABLISH QUORUM | J. Lewis |

3. WELCOME/INTRODUCTIONS

J. Lewis

For additional information regarding this agenda, please contact Michael Brett, 1507 21st Street, Ste. 210 Sacramento, CA 95811, (916) 322-8481.

Documents for an agenda item should be turned into SCDD no later than 12:00 p.m. the day before the meeting to give members time to review the material. The fax number is (916) 443-4957.

4. MEMBER REPORTS

Members

This item is for committee members to provide a report on their legislative and/or public policy activities related to the agency or group they represent. Each person will be afforded up to three minutes to speak.

5. APPROVAL OF JUNE 23, 2015 MINUTES

J. Lewis 4

6. PUBLIC COMMENTS

*This item is for members of the public only to provide comments and/or present information to the Council on matters **not** on the agenda.*

Each person will be afforded up to three minutes to speak. Written requests, if any, will be considered first.

7. OLD BUSINESS (Standing Items)

8

a. Budget Update

N. Nieblas

b. IHHS and CMS Updates

J. Lewis

c. Federal & State Legislation Updates/Council Update on LPPC Bill Package, Elementary & Secondary Education Act & SB 644

N. Nieblas

d. Self-Determination

S. Bingaman

e. Disparity Issues

J. Lewis/All

8. NEW BUSINESS

16

- a. Legislative/Committee Request Form Update J. Fernandez/N. Nieblas
- b. Developmental Center Closures/Policy Statement J. Lewis
- c. United Cerebral Palsy Study N. Nieblas
- d. Special Session Update: AB 2x 4, Managed Care Organization Tax N. Nieblas
- e. State Plan Survey J. Fernandez
- f. Legislative Platform Update N. Nieblas
- g. Discussion Item on IDD and Law Enforcement All
- h. Awareness of Political Campaigns in the Media N. Nieblas/All

9. ADJOURN

J. Lewis

Item 5
APPROVAL OF JUNE 23, 2015
MINUTES



DRAFT
LPPC Committee Meeting Minutes
June 23, 2015

Attending Members

Janelle Lewis (FA)
April Lopez (FA)
David Forderer (SA)
Jennifer Allen (SA)
Tho Vinh Banh
Connie Lapin (FA)
Sandra Aldana (SA)
Lisa Davidson (FA)

Members Absent

Feda Almaliti

Others Attending

Bob Giovati
Nelly Nieblas
Karim Alipourfard
Michel Brett
Wayne Glusker
Gabriel

1. CALL TO ORDER

Chairperson, Janelle Lewis, (FA) called the meeting to order at 10:10 a.m.

2. ESTABLISH QUORUM

A quorum was established.

3. WELCOME/INTRODUCTIONS

Members and others introduced themselves, as indicated.

4. MEMBER REPORTS

David Forderer (SA), committee member, reported on his meeting with Santi Rogers, the Director of Department of Developmental Services (DDS) regarding developmental center closures. Mr. Forderer will meet with the DDS Director on this issue again.

5. APPROVAL OF MAY 28, 2015 MEETING MINUTES

It was moved by Lisa Davidson(FA) and seconded by Connie Lapin(FA) and unanimously carried (April Lopez (FA) abstained) to approve the May 28, 2015 minutes, with the following corrections:

(See attendance list for voting members)

- 1- Added Lisa Davidson's name to the list of attendees' names, as she was present at the May 28 LPPC Meeting.
- 2- The meeting starting time was corrected to: 10:05 am from 10:05 pm
- 3- On Page 7 item d. the word specially, was changed to especially. For grammatical reasons.

6. PUBLIC COMMENTS

Lisa Davidson was allowed to make a public comment on behalf of LA RAC on various issues.

7. OLD BUSINESS

a) **Budget:** Bob Giovati and members discussed :

Budget as a whole and issues regarding the effect of the May Revise on DD system in general and the Lanterman Coalition issues in particular.

Money for Intellectual and Developmental Disabilities (I/DD): The final budget will depend on legislative leaders negotiating with Governor Brown.

Issue of priority for legislators: There are different versions in the Assembly and the Senate dealing with I/DD budget issues.

Money from pending and future DC closures should be going to I/DD programs instead of the general fund.

Budget Committees: it is important that SCDD Legislative Staff be present at the budget hearings for explanation and representation.

SCDD's possible participation in Lanterman Coalition activities was discussed.

b) In Home Supportive Services (IHSS) and Centers for Medicare-Medicaid (CMS) Services

Connie Lapin (FA) discussed IHSS and CMS in detail and explained challenging problems facing all sides of the issues.

Person Centered Planning:

(Forderer) (SA) made a motion and (Lapin) (FA) seconded to request SSAN to do fact sheet for Person Centered Planning. Motion Passed. Jennifer Allen (SA) abstained. No further discussion.

(See attendance list for voting members)

c) Federal and State Legislation

Bob Giovati, Deputy Director of Plans and Programs, gave a general update on the LPPC legislative package.

SB 644: Limited Examination and Appointment Program (LEAP) for persons with developmental disabilities. It was moved by (Forderer) (SA) and seconded by (Davidson) (FA) to support SB 644 if amended. Motion passed.

(See attendance list for voting members)

SB 277: Vaccination and Immunization. It is moving forward. It would eliminate the exemption from current immunization requirement. There was disagreement and unhappiness expressed by chair and other members over the scope of this legislation.

d) Self Determination

Connie Lapin (FA) continues her analysis of self-determination from previous meetings and expanded to include:

e) Disparity Issues

- Minorities (especially Latinos) are diagnosed with autism later than Caucasians.
- Improving socialization and decreasing language disparities.
- Tho Vinh Banh, the member representing Disability Rights of California, spoke the on the obligation of DDS to consult with stakeholders including consumers and families to ease disparity statewide, etc.

8. New Business:

- 1- Legislative Committee Request Form. Staff, Janet Fernandez, assisted by Mr. Giovati, distributed the form to LPPC. The form is not finalized yet and staff is open to relevant ideas and recommendations.
- 2- Developmental Center closures the financial/ social effects were discussed.

9: Adjournment

Chairperson Lewis (FA) adjourned the meeting at 2:55 p.m.

The next LPPC meeting was scheduled for August 25, 2015.

Item 7

OLD BUSINESS

California assisted death bill finished for the year

Senate Bill 128 stalls in Assembly Health Committee

California's controversial assisted death bill is done for the year, according to the Assembly Health Committee.

In an e-mail to legislative offices, committee secretary Patty Rodgers wrote, "The authors will not pursue this bill this year – waiting on a statement from the authors explaining details and future plans."

Senate Bill 128 would have allowed doctors to prescribe lethal drugs to terminally ill patients. It passed the Senate last month, but stalled in the Assembly Health Committee two weeks ago over increasing objections from Latino Democrats.

Past attempts to legalize assisted death in California also collapsed, but SB 128's champions believed that public sentiment had turned in their favor. They also surmounted a major political obstacle when the California Medical Association silenced its longstanding aversion to helping ailing patients die.

But the Catholic Church remained firmly opposed to the bill, arguing that it was an ethical violation. Proponents were not able to sway a majority of members on the Assembly Health Committee, some of whom pointed to personal experiences that counseled them against backing the bill.

"You've got to look at what I've done before the Legislature ... working to help save and protect peoples' lives, giving that option – a second chance at life," Assemblyman Freddie Rodriguez, D-Pomona, who worked as an emergency medical technician, said Monday. "Letting folks have that option to end their life, it's just something I can't come to grips with."

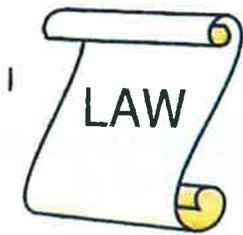
Some members denied that religious objections were a decisive factor.

"There are times when I can be in clear policy opposition to the church – clearly with a pro-choice stand as a Democrat, I can say 'no' to the church,"

Assemblyman Miguel Santiago, D-Los Angeles, a practicing Catholic who once weighed entering the seminary, said on Monday. "It's more of an internal struggle of how to look at the end of life more than any impact of religious or political" pressure.

Alexei Koseff: 916-321-5236, @akoseff. Jeremy B. White of The Bee Capitol Bureau contributed to this report.

[Read more here: http://www.sacbee.com/news/politics-government/capitol-alert/article26660032.html#storylink=cpy](http://www.sacbee.com/news/politics-government/capitol-alert/article26660032.html#storylink=cpy)



LPPC AGENDA ITEM DETAIL SHEET

BILL: SB 644, as amended, Hancock. Limited Examination and Appointment Program: persons with developmental disabilities.

ISSUE: The Limited Examination and Appointment Program (LEAP) was established as an alternative to the traditional civil service examination and appointment process to facilitate the hiring of persons with disabilities in the state civil service.

SUMMARY: SB 644 allows a successful internship performance at a State agency as the indicator as to whether an individual with intellectual or developmental disability is eligible for State civil service employment.

BACKGROUND/ISSUE/ANALYSIS: Jobseekers with disabilities living in California are certified eligible for LEAP through the state's Department of Rehabilitation. Once an individual receives a certification, that individual can apply for LEAP examinations during open testing periods (and they may also continue to apply for non-LEAP examinations as well). All examinations are provided online as well as by mail. After successfully passing the examination, the candidate will then be appointed to the civil service classification.

However, *LEAP is often not an effective alternative* to the standard civil service examination for individuals with *I/DD* because it relies on a written test to initially evaluate candidates. Many people with *I/DD* can successfully be employed in jobs involving complex tasks but need time and customized training to learn the job. Written tests are not a valid measure of their abilities.

DISCUSSION: This bill was originally presented to the LPPC during the April 2015 meeting. However, it has been substantially amended since the LPPC first reviewed it.

This bill would preclude an examination for a person with a developmental disability from including a written examination or readiness evaluation and would, instead, require that the competitive examination consist of an internship with a state agency that is not less than 512 hours (down from the original figure of 1,024 hours) in duration, and require the department to refer the names of eligible applicants who successfully complete the internship to the appointing powers for examination appointments.

It would not require people with *I/DD* to utilize the internship. Rather, they could decide to use the standard LEAP process if they believe they meet the qualifications for the job and feel they can pass the written exam.

The bill would require the department to create that internship program in coordination with the State Department of Developmental Services and the Department of Rehabilitation, as specified.

The bill would also authorize a state agency that provides the internship or appoints a person with a developmental disability to a position under LEAP to allow that person to receive on-the-job support and finance the internship or position with personnel funds or other available funds assigned to a vacant or unfilled position, as specified, but would provide that on-the-job support services are not the financial or programmatic responsibility of any state agency engaged in establishing the LEAP internship process. The bill would specify that LEAP is not a mandate on any state agency employer or job applicant except to the extent specifically directed by the State Personnel Board.

RECOMMENDATION: In their June meeting, the LPPC voted to “**Support If Amended**”, if the amendments clarified and solidified the new parameters of the bill already articulated in this detail sheet. However, while SCDD staff has confirmed with the author’s office that such amendments will in fact be made, they were not in print at the time this detail sheet was prepared

UPDATE:

As of June 30, 2015 the bill has been amended to include the specified parameters outlined in this detail. It is currently in the suspense file in appropriations in the Assembly, after confirming with Hancock staff, the bill is set to be heard in a suspense hearing the last week of August

COUNCIL STRATEGIC PLAN OBJECTIVE: Goal 8: Employment. The State of California will adopt an Employment First policy which reflects inclusive and gainful employment as the preferred outcome for working age individuals with developmental disabilities

ATTACHMENTS: None.

PREPARED: Bob Giovati/Nelly Nieblas

Statewide Self-Determination Program Update August 6, 2015

The Legislature finds that in each of the 56 states and territories, the federal Developmental Disabilities Assistance and Bill of Rights Act of 2000 (Public Law 106–402 (42 U.S.C. 15001 et seq.)) establishes State Councils on Developmental Disabilities that work to promote the core values of the act, including self-determination, independence, productivity, integration, and inclusion in all aspects of community life.

Overview

The Department of Developmental Services (DDS) shall implement a statewide Self-Determination Program. The Self-Determination Program shall be available in every regional center catchment area to provide participants and their families, within an individual budget, increased flexibility and choice, and greater control over decisions, resources, and needed and desired services and supports to implement their IPP. The statewide Self-Determination Program shall be phased in over three years, and during this phase-in period, shall serve up to 2,500 regional center consumers. Following the phase-in period, the program shall be available on a voluntary basis to all regional center consumers who are eligible for the Self-Determination Program. The program shall be available to individuals who reflect the disability, ethnic, and geographic diversity of the state.

“Self-Determination” means a voluntary delivery system consisting of a defined and comprehensive mix of services and supports, selected and directed by a participant through person-centered planning, in order to meet the objectives in his or her IPP. Self-Determination services and supports are designed to assist the participant to achieve personally defined outcomes in community settings that promote inclusion. The Self-Determination Program shall only fund services and supports provided pursuant to this division that the federal Centers for Medicare and Medicaid Services determines are eligible for federal financial participation.

Role of SCDD

Each regional center shall establish a local volunteer advisory committee to provide oversight of the Self-Determination Program. The regional center and the State Council on Developmental Disabilities shall each appoint one-half of the membership of the committee and, in addition, shall include the regional center clients’ rights advocate (from OCRA). The committee shall consist of consumers, family members, and other advocates, and community leaders.

The State Council on Developmental Disabilities shall form a volunteer committee, to be known as the Statewide Self-Determination Advisory Committee, comprised of the chairs of the 21 local advisory committees or their designees. The council shall convene the Statewide Self-Determination Advisory Committee twice annually, or more frequently in the sole discretion of the council.

The State Council on Developmental Disabilities, in collaboration with the protection and advocacy agency may work with regional centers to survey participants regarding participant satisfaction under the Self-Determination Program and, when data is available, the traditional service delivery system, including the proportion of participants who report that their choices and decisions are respected and supported and who report that they are able to recruit and hire qualified service providers, and to identify barriers to participation and recommendations for improvement.

The Council, in collaboration with the protection and advocacy agency shall issue a report to the Legislature, no later than three years following the approval of the federal funding on the status of the Self-Determination Program and provide recommendations to enhance the effectiveness of the program. This review shall include the program's effectiveness in furthering the principles of self-determination, including all of the following:

- **Freedom**, which includes the ability of adults with developmental disabilities to exercise the same rights as all citizens to establish, with freely chosen supporters, family and friends, where they want to live, with whom they want to live, how their time will be occupied, and who supports them; and for families to have the freedom to receive unbiased assistance of their own choosing when developing a plan and to select all personnel and supports to further the life goals of a minor child.
- **Authority**, which includes the ability of a person with a disability, or family, to control a certain sum of dollars in order to purchase services and supports of their choosing.
- **Support**, which includes the ability to arrange resources and personnel, both formal and informal, that will assist a person with a disability to live a life in his or her community that is rich in community participation and contributions.
- **Responsibility**, which includes the ability of participants to take responsibility for decisions in their own lives and to be accountable for the use of public dollars, and to accept a valued role in their community through, for example, competitive employment, organizational affiliations, spiritual development, and general caring of others in their community.
- **Confirmation**, which includes confirmation of the critical role of participants and their families in making decisions in their own lives and designing and operating the system that they rely on.

Facts on Self-Determination

Eligibility

- Have a developmental disability and currently receiving services from a regional center or be a new consumer of a regional center.
- Be over the age of 3.
- Live at home, in the community, or in a group home. An individual who lives in a licensed long-term health care facility (i.e., a Skilled Nursing Facility, Intermediate Care Facility, or a Developmental Center) is not eligible to participate in the Self-Determination Program unless you are transitioning from that facility.
- Be a responsible participant including attending an orientation/training and working with a Fiscal Manager.

Services and supports

- The consumer and/or planning team who determines the services and supports needed.
- Consumers are not required to use agencies vendored by the Regional Center.
- Consumers will have the same rights established under the traditional service model (e.g. appeals, eligibility determinations, all rights associated with the IPP process).

Independent Facilitator

- A person hired by the consumer to assist in their person centered plan.
 - It is wise to have a person who is experienced in the broad range of services and opportunities in the community, to assist consumers in reaching your goals.
- Must be a person who does not provide services to the consumer.
- Regional Center Service Coordinators may provide the services and supports necessary to implement the IPP, if a consumer elects not to use an independent facilitator.

Individual Budget

- The amount of regional center funding available to purchase services and supports needed to implement the IPP.
 - For current regional center consumers, the budget will equal 100% of the amount of the total expenditures made by the regional center on services during the past 12 months. This amount can be adjusted, up or down, if the IPP team determines that the individual's needs, circumstances, or resources has changed. Additionally, the IPP team may adjust the budget to support any prior needs or resources that were not addressed in the IPP.
 - For consumers new to the regional center, the individual budget amount is determined by the IPP team, and is based upon the average POS cost of services and supports, paid by the regional center, that are identified in the individual's IPP. The average cost may be adjusted, up or down, by the regional center, if needed to meet the individual's unique needs.

Financial Management Service (FMS)

- Required, consumers must have an FMS. The FMS is responsible must:
 - Manage and direct the funds contained in the individual budget.
 - Pay the bills to the individuals and organizations that provide support services.
 - Provide a monthly accounting of how funds are being spent on an individual budget.
 - Advise and assist in the facilitation of hiring service and support workers and ensure that all employment laws are being followed.
 - The FMS will be paid from the Individual Budget.

The Self-Determination Program will provide consumers and their families with more freedom, control, and responsibility in choosing services and supports to help them meet objectives in their Individual Program Plan.

Self-Determination Program Waiver Application Status or “Where are we now?”

Implementation of the Self-Determination Program (SDP) is contingent upon approval of federal funding. The Department of Developmental Services (DDS), in consultation with stakeholders, drafted a 1915 (c) Home and Community-Based Services (HCBS) Waiver application that was submitted to the federal Centers for Medicare and Medicaid Services (CMS) on December 31, 2014. Subsequently, CMS asked follow-up questions related to recently enacted federal regulations and policies regarding 1) public input for Waiver applications; and, 2) federal requirements for HCBS settings. DDS, in conjunction with the Department of Health Care Services (DHCS), has had a number of discussions with CMS and provided follow-up information CMS requested. DDS is in the process of posting the Waiver for public input. After 30 days of public input, the final draft will be submitted to CMS. Final approval could take 90 days or longer.

Once the Waiver is approved, the SDP will be available Statewide for up to 2,500 participants during the first three years of the program. Participation in SDP is voluntary. DDS will select the individuals who can participate in the first 3 year phase from a list of consumers who have attended an orientation and are interested in the program. After 3 years, the SDP will be open to any consumers (over the age of 3) who would like to participate. Consumers can transfer back to traditional case management services at any time.

The State Council on Developmental Disabilities (SCDD) is committed to the implementation of the Self-Determination Program. SDP regulations are consistent with the long-standing principles of the State of California's Lanterman Developmental Disabilities Services Act (Lanterman Act) for community integration and participation as well as the Federal Government's CMS rules. A SDP advisory group has been formed to assist DDS in shaping the framework of the SDP based on the law that authorizes the program. SCDD staff (Aaron Carruthers and Sonya Bingaman) are members of the SDP Advisory group which is focused on developing, implementing, and continuing compliance with the federal HCBS requirements. Advisory group members represent the various interests and perspectives impacted by the HCBS regulations by including consumers, family members, providers, regional centers, and advocates. SCDD is informed about partner agencies, DDS, DHCS and CMS.

SCDD staff are also involved with Work Groups of the SDP Advisory Committee to develop training materials for regional center staff and the community. A Self-Determination introduction video produced by DDS, as well as training modules, will be ready in the coming month.

Prepared for the LPPC and Executive Committee meetings by SCDD Sacramento Office staff.

BREAKING NEWS
August 7, 2015

At the request of the federal government, new language was added to the Self-Determination Program (SDP) Waiver application describing how homes and settings where SDP participants will reside and receive services meet the requirements of the federal home and community-based settings rules that became effective in March 2014.

As a result of this change, the Department is required to repost the Waiver application for at least 30 days.

The Waiver application will be formally resubmitted to the Centers for Medicare and Medicaid Services shortly after the public comment period, which ends on September 7, 2015.

Comments or requests to review a hardcopy of the application can be submitted by:

e-mail : sdp@dds.ca.gov

phone: (916) 653-7710

or in writing to:

**Department of Developmental Services (DDS)
Attention Community Services Division
1600 Ninth Street, Room 320
MS 3-8
Sacramento, CA 95814**

Item 8

NEW BUSINESS

Policy Statement: Closure of Sonoma Developmental Center (Draft 2)

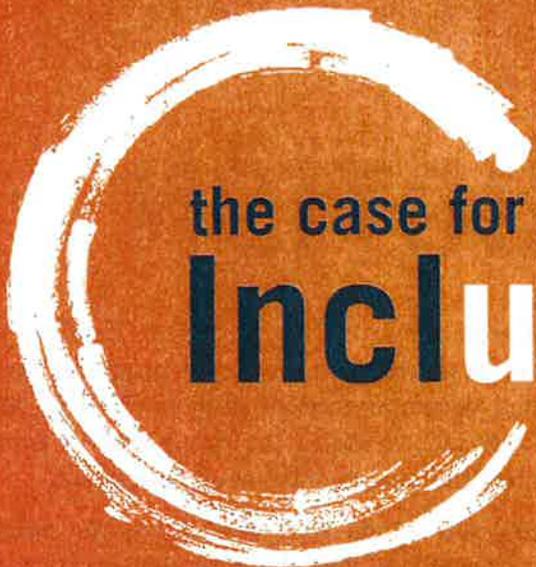
The State Council on Developmental Disabilities (SCDD) has a role in ensuring that individuals with intellectual/developmental disabilities and their families receive the services and supports needed to be fully integrated into the community. As in the case for developmental centers there should be a detailed, concise and holistic transition plan for clients leaving institutional settings going into community living.

On July 14, 2015 the State Council on Developmental Disabilities (SCDD) had a presentation from Director of Developmental Disabilities Services, Santi Rogers. At this meeting plans were discussed for the closure of Sonoma Developmental Center (SDC), one of California's remaining institutions.

SCDD has recommendations for the closure of the Sonoma Developmental Center, a detailed plan of how the closure of Sonoma Developmental Center will be monitored is required to ensure proper procedures are followed. The clients from Sonoma must have access to health care and other supports available before and after the transition to community living. The Department of Developmental services must have affordable housing, including an array of housing options available to meet their clients' needs. The SCDD Clients' Rights Advocate inside the DC will continue to protect and advocate for the rights of people transitioning into the community from SDC. The SCDD Volunteer Advocacy Services (VAS) project advocates for SDC residents without involved families or conservators both during SDC residency and six months post community placement. The VAS project should extend beyond a year post placement to assure continuity of care and successful community transition.

Upon the closure of the Sonoma Developmental Center, SCDD recommends outreach to the local community informing them of key changes. Seeking the community's cooperation is essential to an inclusive outreach strategy. A clear process should be set forth in the disposition of the land and other assets at Sonoma once the shutdown is complete. Clear guidelines must be developed for the use of money saved from the closure of the Sonoma Developmental Center. These funds must be a long-term investment in the future of people with intellectual and/or developmental disabilities for living in their communities.

The California State Council on Developmental Disabilities poses these recommendations to ensure that fair and equitable supports exist for Sonoma clients as they transition into community living.



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.

¹The 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	9	RTC		
		% of ID/DD Expenditures on HCBS	7	7	RTC		
		% of ID/DD Expenditures on Non-ICF-MR	8	8	Coleman		
	Residential	1-3 Residents - %	13	13	RTC		
	Services in the Community	1-6 Residents -%	11	50	11	50	RTC
	(includes all types)	16+ Residents % (smaller %, higher rank)	-4	-4	RTC		
		% in Large State Facilities	-3	-3	RTC		
Tracking Health, Safety & Quality of Life	Waivers Promoting Self-Determination		2		NCI		
	NCI - % Self-Directed		6	0			
	Quality Assurance - NCI Participation			2.8		NCI	
	NCI - Recent Dental Visit			2.8		NCI	
	NCI - Lonely Less than Half the Time		12	2.8	14	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 Abuse		6				
	Keeping Families Together	Family Support per 100k	6	12	3	8	Coleman
		% in a Family Home			2		NCI
NCI - Child/Family Survey Participation				2		Mathematica	
Promoting Productivity	Has Medicaid Buy-In Program	2		2		ICI	
	Competitive Employment - %	6.5		4.0			
	Voc Rehab - per 100k	1.5	10		12		
	Voc Rehab - Rehab Rate (finding a job)			2		ICI	
	Voc Rehab - Number of Hours Worked			2		ICI	
Reaching Those in Need	Voc Rehab - Retain Job for One Year			2		ICI	
	Waiting List - Average % Growth for Residential and HCBS	9		9		RTC,Kaiser	
	Individuals with ID/DD Served per 100k of Population	3	16	2	16	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 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 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	States	2015 Ranking
Arizona	1	Tennessee	32
Maryland	2	Wisconsin	33
Missouri	3	North Carolina	34
New York	4	Delaware	35
Hawaii	5	New Mexico	36
Colorado	6	Nebraska	37
Minnesota	7	South Dakota	38
Dist. of Columbia	8	Rhode Island	39
South Carolina	9	Alaska	40
Ohio	10	Virginia	41
Georgia	11	North Dakota	42
Maine	12	Oklahoma	43
Alabama	13	Iowa	44
Massachusetts	14	Wyoming	45
Utah	15	Idaho	46
California	16	Illinois	47
Connecticut	17	Montana	48
Oregon	18	Arkansas	49
Kentucky	19	Texas	50
Kansas	20	Mississippi	51
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		

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



↑38
PLACES

of individuals isolated in large State institutions, and started participating in and reporting outcomes for the NCI.

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.



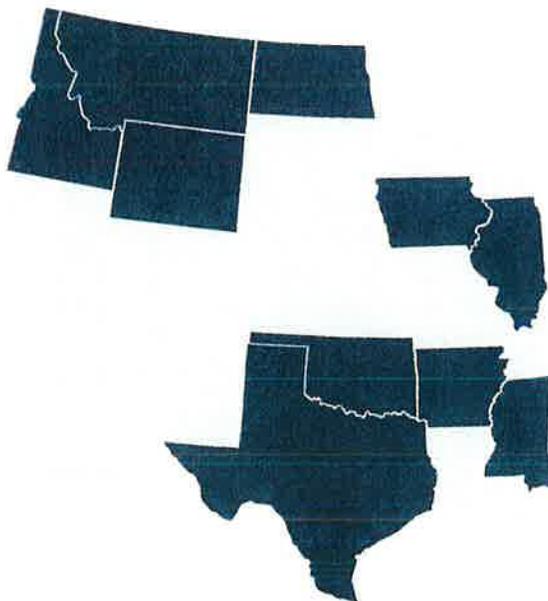
THE BEST, THE WORST AND FACTS ABOUT THE TOP 10

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

Transparency

2

Personalization
& Prioritization

3

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].”

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.

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

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.

– 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 youthⁱⁱ:

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 Yearsⁱⁱⁱ

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
3 Enjoyment of Life	Medium family income	2x more likely to be enrolled
	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:

- | | |
|---|--|
| <p>1 Received work experiences</p> <ul style="list-style-type: none"> • As evidenced by percent of school day in work experiences • Only 57% reported having work experiences <p>2 Received youth involvement</p> <ul style="list-style-type: none"> • As evidenced by their involvement in transition planning • Only 58% reported involving youth <p>3 Had family involvement</p> <ul style="list-style-type: none"> • As evidenced by family involvement in transition planning | <p>4 Had life skills instruction</p> <ul style="list-style-type: none"> • As evidenced by student receiving life skills or social skills instruction • 72% reported receiving this <p>5 Enjoyed interagency involvement</p> <ul style="list-style-type: none"> • 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^y answers this with the curriculum and teaching methods that best produce the desired experience or outcome.

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

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	% of Recipients with ID/DD on HCBS	9
	Community-Based % of ID/DD Expenditures on HCBS	7
	% of ID/DD Expenditures on non-ICF-MR	8
	1-3 Residents %	13
	1-6 Residents %	11
	16+ Residents % (smaller %, higher rank)	-4
	% in Large State Facilities	-3
Tracking Health, Safety & Quality of Life	NCI - % Self-Directed	2
	Quality Assurance - NCI Participation	0
	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
	% in a Family Home	3
	NCI - Child/Family Survey Participation	2
Promoting Productivity	Has Medicaid Buy-In Program	2
	Competitive Employment - %	4.0
	Voc Rehab - Rehab Rate (finding a job)	2
	Voc Rehab - Number of Hours Worked	2
Reaching Those in Need	Voc Rehab - Retain Job for One Year	2
	Waiting List - Average % Growth for Residential and HCBS	9
	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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COUNCIL AGENDA ITEM DETAIL SHEET

BILL: AB 2x 4, Levine Managed Care Organization Tax

ISSUE: In 2011 the California legislature passed AB 97 which implemented a 10% provider payment reduction to most categories of services in Medi-Cal. In 2013 Gov. Brown issued an 8% cut in IHSS hours in response to a federal court ruling including is 7% cut the following year. AB 2x 4 would create a flat managed-care tax of \$7.88 per person per month to generate 1.878 billion in annual revenue.

SUMMARY: AB 2x 4 is aimed at addressing the budget cuts imposed by AB 97 in 2011 and subsequent budget cuts made in 2013 to the In-Home Supportive Services (IHSS) program. This bill would fully fund the 1.1 billion needed for Medi-Cal, restore medical rates to pre-AB 97 levels. This bill would also reinstate IHSS service hours and increase developmental services funding.

BACKGROUND/ISSUES/ANALYSIS:

Existing law imposes a sales tax on providers of support services for the privilege of selling support services. Existing law also imposes a sales tax on sellers of Medi-Cal managed care plans. This bill would repeal the support services sales tax and would establish a new managed care organization provider tax. It would require the Department of Health Care Services to request approval from the federal Centers for Medicare and Medicaid Services as necessary to implement the bill.

AB2x 4 establish the Health and Human Services Special Fund in the State Treasury, into which all revenues, in which all revenues will be deposited. The remaining moneys in the fund would be available to the department for the purpose of funding the nonfederal share of Medi-Cal managed care rates.

RECOMMENDATION: Support AB 2x 4 (Levine)

COUNCIL STRATEGIC PLAN OBJECTIVE: Goal# 10: Health.
Individuals with developmental disabilities understand their options

regarding health services and have access to a full range of coordinated health, dental and mental health services in their community.

ATTACHMENTS: None.

PREPARED: Nelly Nieblas



OFFICE OF ASSEMBLYMEMBER

Marc Levine

TENTH ASSEMBLY DISTRICT

AB 2x 4: Managed Care Organization Tax

SUMMARY

AB 2x 4 would create a flat Managed Care Organization (MCO) tax of \$7.88 per person per month to generate \$1.878 billion in annual revenue for the following purposes:

- Fully fund the \$1.1 billion needed for Medi-Cal;
Restore Medi-Cal rates to pre-AB 97 levels;
Reinstate In-Home Supportive Services (IHSS) hours; and
Increase Developmental Services funding.

EXISTING LAW/BACKGROUND

Medi-Cal

Medi-Cal, California's Medicaid program, is a public health insurance program that provides comprehensive health care services at little or no cost to low-income individuals. Due to the implementation of health care reform, California now has more than 12 million people enrolled in Medi-Cal, which covers about 32% of our State's population.

As a result of significant budget cuts, the Legislature passed AB 97 in 2011, which implemented a 10% provider payment reduction to most categories of services in Medi-Cal. Since then, providers have struggled to provide essential services for Medi-Cal patients for little reimbursement. Medi-Cal General Fund spending is projected to increase 4.3 percent from \$17.8 billion in 2014-15 to \$18.6 billion in 2015-16.

A stable source of funding must be developed to fund the Medi-Cal program.

IHSS

In-Home Supportive Services (IHSS) provides low-income individuals who are elderly or disabled with personal assistance and other services so they can live safely in their homes.

In 2013, Governor Brown issued an 8% cut in IHSS hours in response to a Federal Court ruling, followed by a 7% cut the following year. In response, the 2015 Budget includes a one-time General Fund augmentation of \$226 million in 2015-16 to partially restore service hours.

A stable source of funding must be developed to continue this reinstatement of IHSS hours.

Developmental Services

The Department of Developmental Services operates two branches of service delivery to aid our State's most vulnerable and developmentally disabled populations: the regional centers and the developmental centers.

The regional centers serve more than 200,000 clients across 21 non-profit centers that coordinate supportive services for individuals with developmental disabilities. There are approximately 1,000 individuals remaining in California's four developmental centers.

The 2015 budget has proposed a closure plan for the State's remaining developmental center residents, meaning that severely medically and behaviorally fragile patients will need to transition to adequate care in the community and will need a source of reliable funding.

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MCO Tax

Managed Care Organizations (MCOs) are a type of health care delivery that seeks to reduce costs and improve patient care by contracting with a network of providers. Essentially, MCOs are HMOs and PPOs.

California has been able to leverage federal funding by taxing Medi-Cal enrollment at MCOs for the past several years. However, in 2014 the Federal Centers for Medicare and Medicaid Services informed California that the current MCO tax structure is inconsistent with federal Medicaid regulations and will not be allowed after its expiration in 2016. This effectively puts California at risk of losing \$1.1 billion in federal matching dollars unless the MCO tax is restructured.

In January, the Governor proposed a tiered tax that ranges from as low as \$0.75 per person per month to a rate as high as \$25.25 per person per month, depending on the size of the membership plan. While that proposal provided a valuable start to the discussion, it has not been introduced into a bill as a formal proposal for legislative consideration in the regular session, the budget process, or the extraordinary session.

AB 2x 4 instead creates a flat MCO tax and steady revenue for Medi-Cal, IHSS, and Developmental Services. This stable revenue, regardless of marketplace changes, will ensure the Legislature is not revisiting the MCO tax structure again in future years due to a lack of revenue generation.

In the absence of a new MCO tax, the Governor and the Legislature would have to make \$1.1 billion in cuts for the 2016-17 budget year, and each year thereafter. Making cuts in vital services, instead of creating a reliable funding source, is simply unacceptable. Nor can we allow the Medi-Cal program to fail. We also cannot ignore the

need to fund IHSS and developmental services and to restore Medi-Cal reimbursement rates.

Now is the time to take action on this important issue. The communities relying upon funding need the Legislature to act now. California cannot enter 2016 without a resolution to these significant funding questions. Nor we afford to spend months while the Legislature determines whether this tax burden can fall elsewhere.

THIS BILL

AB 2x 4 creates a flat MCO tax that will provide a stable stream of revenue to fund critical public programs. By charging a flat per person per month fee of \$7.88 beginning July 1, 2016, the State can annually generate enough revenue to:

- Receive the \$1.1 billion in matching federal Medicaid funds;
- Reinstate the IHSS 7% wage cuts;
- Restore Medi-Cal reimbursement rates to pre-AB 97 levels; and
- Provide necessary funding for the developmental disabilities community.

In the event of any excess, this bill ensures that all additional revenue generated is directed towards further Medi-Cal rate increases. In addition, AB 2x 4 would require health plants to report enrollment data to the Department of Managed Health Care on a quarterly basis.

SUPPORT

Morningside Adult Day Health Care Center

Staff Contact: Michael Miiller or Sofia Andrade
 michael.miiller@asm.ca.gov or sofia.andrade@asm.ca.gov (916) 319-2010

Last updated: 07/22/15

(ORGANIZATION LETTER HEAD, IF APPLICABLE)

July 24, 2015

Assemblymember Marc Levine
California State Capitol Room 2141
Sacramento CA, 94814

Re: AB 2x 4 (Levine)—SUPPORT

Dear Assemblymember Levine,

On behalf of **(name of organization)**, I am writing to express our strong support of AB 2x 4 (Levine). This bill will create a flat Managed Care Organization (MCO) tax to restore and preserve vital funding for California's Medi-Cal, In-Home Supportive Services (IHSS), and Developmental Services.

For far too long, California has cut these fundamental public health services again and again. We now face entire provider networks in crisis, not able to adequately serve our state's most vulnerable citizens. Patients have suffered long enough from limited access to essential services. Medi-Cal Patients are being denied access to doctors due to low reimbursement rates; IHSS patients have faced cuts in hours available to them; and the developmentally disabled community is in need of critical investment in provider services.

This bill would provide a stable and reliable funding source to provide the care and support these populations need and deserve to achieve the safe, healthy and fulfilling quality of life we all deserve.

For the above reasons, we strongly support AB 2x 4. If you have any questions, please contact **(contact person)** at **(contact number)**.

Sincerely,

Name
Title, Organization



Draft

LEGISLATIVE
and Public Policy
Platform

Approved 2014

About the Council

The federal Developmental Disabilities Assistance and Bill of Rights Act of 2000 establishes State Councils on Developmental Disabilities in each of the 56 states and territories to promote self-determination, independence, productivity, integration, and inclusion in all aspects of community life for people with intellectual and developmental disabilities (IDD) and their families. The Lanterman Act establishes the California State Council on Developmental Disabilities (Council) to fulfill those obligations through advocacy, capacity building, and systems change.

To that end, the Council develops and implements goals, objectives, and strategies designed to improve and enhance the availability and quality of services and supports.

The Council is comprised of 31 members appointed by the Governor, including individuals with disabilities and their families, and representatives from Disability Rights California, the University Centers for Excellence in Developmental Disabilities, and state agencies.

In addition to the Council's Sacramento headquarters, 13 regional offices support individuals with IDD and their families through activities such as advocacy training, monitoring, and public information. The Council strives to ensure that appropriate laws, regulations, and policies pertaining to the rights of individuals are observed and protected.

This document conveys the Council's position on major policy issues that affect individuals with IDD and their families.



SELF-DETERMINATION

Individuals with IDD and their families must be given the option to control their service dollars and their services through Self-Determination. With the support of those they choose and trust, people with IDD and their families are best suited to understand their own unique needs, develop their own life goals, and construct those services and supports most appropriate to reach their full potential. Self-Determination gives individuals the tools and the basic human right to pursue life, liberty, and happiness in the ways that they choose.



EMPLOYMENT

A regular job with competitive pay gives people an opportunity to contribute and be valued at a work site; it gives them a chance to build relationships with co-workers, be a part of their communities, and contribute to their local economies. It reduces poverty and reliance on state support, and it provides a life of greater dignity.

Integrated competitive employment is the priority outcome for working age individuals with IDD, regardless of the severity of their disability. Policies and practices must set expectations for employment, promote collaboration between state agencies, and remove barriers to integrated competitive employment through access to information, benefits counseling, job training, postsecondary education, and appropriate provider rates that incentivize quality employment outcomes.

EQUITY

Regional center services and supports must be distributed equitably so that individuals receive culturally and linguistically competent services and supports that meet their needs, regardless of their race, ethnicity, or income. Disparities in services can result in severe health, economic, and quality of life consequences.



TRANSPORTATION

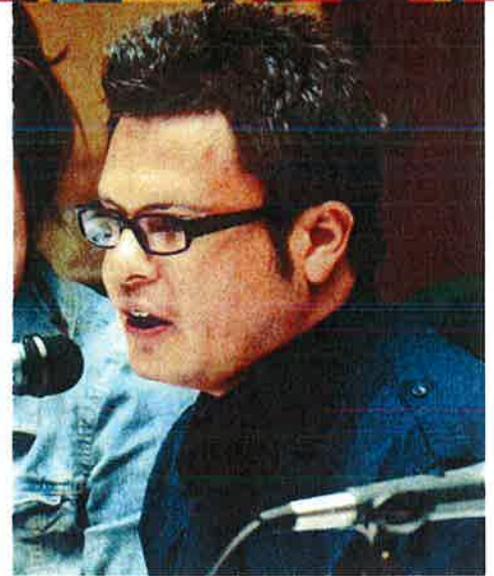
Access to transportation is essential to the education, employment, and inclusion of individuals with disabilities. Individuals with IDD must be a part of transportation planning and policymaking to assure their needs and perspectives are heard and addressed. Mobility training must be a standard program among public transportation providers to increase the use of public transportation and reduce reliance on more costly segregated systems.

HEALTH CARE

Individuals must be reimbursed for insurance co-pays, co-insurance, and deductibles, when their health insurance covers therapies that are on their IPPs.

California has an obligation to assure that individuals with disabilities have continuity of care, a full continuum of health care services and equipment, and access to plain language information and supports to make informed decisions about their health care options.

California has an obligation to support the health care of individuals with IDD. This includes people with multiple health care needs, those who require routine preventative care, mental health treatment, dental care, durable medical equipment, and those with gender specific health issues.



EDUCATION

Schools must implement the goals of the Individuals with Disabilities Education Act (IDEA) to provide children with disabilities with free appropriate public education and prepare them for post-secondary education, employment, and independent living. Students with disabilities will be educated alongside their non-disabled peers in the least restrictive environment. School districts and other educational authorities need to be held accountable for implementing the letter and the intent of IDEA, in all aspects, including measurable postsecondary goals.

HOUSING

Community integrated living options for individuals with IDD must be increased and enhanced through access to housing subsidy programs and neighborhood education to reduce discrimination. Permanent, affordable, accessible, and sustained housing options must be continually developed to meet both current and future needs.

SELF-ADVOCACY

Individuals with IDD must be supported to exert maximum control over their lives. They must be provided the opportunity and support to assume their rightful leadership in the service system and society, including voting and other civic responsibilities. Self-advocates must have access to enhanced training, plain language materials, and policy making opportunities.

COMMUNITY PARTICIPATION

Individuals with IDD must have access to and be supported to participate in their communities, with their non-disabled peers, through opportunities such as education, employment, recreation, organizational affiliations, spiritual development, and civic responsibilities.

TRANSITION TO ADULT LIFE

Education, rehabilitation, and regional center services must support students to transition to integrated competitive employment or post-secondary educational opportunities that will lead to employment. Successful strategies include starting career exploration at age 14, coordination among systems, youth empowerment in their education and service planning, integrated work experiences, family engagement, and a seamless transition to post-secondary work or education.



RATES FOR SERVICES

The state must restore rates to adequately support the availability of quality services for people with all disabilities in all the systems that serve them. A planned and systematic approach to rate adjustments must prioritize and incentivize services and supports that best promotes self-determination, independence, employment, and inclusion in all aspects of community life.

VICTIMS OF CRIME

All people have a right to be safe; however, individuals with IDD experience a much greater rate of victimization, and a far lower rate of prosecution for crimes against them, than does the general public. The same level of due process protections must be provided to all people. Individuals with IDD need to be trained in personal safety, how to protect themselves against becoming victims of crime, and how their participation in identification and prosecution can make a difference. Law enforcement personnel must be trained in how to work with people with IDD who they interact with during the course of their duties, including those who are victims of crimes.



QUALITY OF SERVICES AND SUPPORTS

The State of California must ensure that funding is used to achieve positive outcomes for individuals with IDD and their families. The state must streamline burdensome and duplicative regulations and processes that do not lead to positive outcomes for people with IDD and their families. Quality assessment and oversight must be provided by the state; it must measure what matters, be administered in a culturally competent manner, and the results made public and used to improve the system of services and supports.



Promise of the Lanterman Act

The Lanterman Act promises to honor the needs and choices of individuals with IDD by establishing an array of quality services throughout the state. Services shall support people to live integrated, productive lives in their home communities, in the least restrictive environment. Access to needed services and supports must not be undermined through categorical service elimination, service caps, means testing, or family cost participation fees and other financial barriers. California must not impose artificial limitations or reductions in community-based services and supports that would compromise the health and safety of persons with IDD.



California State Council Regional Offices

North Coast (707) 463-4700

**Counties Served: Del Norte,
Humboldt, Lake, Mendocino**

North State (530) 895-4027

**Counties Served: Butte, Glenn,
Lassen, Plumas, Modoc,
Shasta, Siskiyou, Tehama, Trinity**

Sacramento (916) 263-3085

**Counties Served: Alpine, Colusa,
El Dorado, Nevada, Placer,
Sacramento, Sutter, Yolo, Yuba, Sierra**

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