



## **STATE PLAN COMMITTEE (SPC) MEETING NOTICE/AGENDA**

Posted at [www.scdd.ca.gov](http://www.scdd.ca.gov)

**DATE:** October 27, 2014

**TIME:** 1:00 p.m. – 4:00 p.m.

**LOCATION:** State Council on Developmental Disabilities  
1507 21<sup>st</sup> Street, Suite 210  
Sacramento, CA 95811  
916/322-8481

### **TELECONFERENCE SITES:**

**Palo Verde District Library**  
125 W. Chanslorway  
Blythe, CA 92225  
(760) 922-5371

**Resources for Independence of  
Central Valley**  
220 N. Santa Fe Ste. 131  
Visalia, CA 93292  
(209) 725-9153

*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](mailto:michael.brett@scdd.ca.gov) by 5 pm on October 21, 2014.*

- 1. CALL TO ORDER** N. Clyde
- 2. ESTABLISHMENT OF QUORUM** N. Clyde
- 3. WELCOME AND INTRODUCTIONS** N. Clyde

<b>4. APPROVAL OF AUGUST 25, 2014 MINUTES</b>	N. Clyde	Page <b>3</b>
<b>5. PUBLIC COMMENTS</b>		
<i>This item is for members of the public to comment and/or present information to the Council. Each person will be afforded up to three minutes to speak. Written requests, if any, will be considered first. The Council will also provide a public comment period, not to exceed a total of seven minutes, for public comment prior to action on each agenda item.</i>		
<b>6. MTARS UPDATE</b>	A. Carruthers	<b>11</b>
<b>7. PPR REPORTING FORMAT</b>	J. Fernandez	<b>33</b>
<b>8. STATE PLAN TIMELINE</b>	J. Fernandez	<b>37</b>
<b>9. DATA COLLECTION FOR STATE PLANS</b>	N. Clyde	
<b>10. EXAMPLES OF OTHER STATE PLANS</b>	N. Clyde	<b>45</b>
<b>11. VISIONS FOR COUNCIL'S FUTURE</b>	A. Carruthers	<b>139</b>

# State Plan Committee

(Draft) Meeting minutes for August 25, 2014  
SCDD Headquarters – Sacramento, CA

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## Members Present:

Jonathan Clarkson  
Nancy Clyde (Chair)  
Rebecca Donabed (Phone attendance)  
Carmela Garnica (Phone attendance)  
Robin Hansen  
Sandra Smith  
Martin Weil

## Others in Attendance:

Molly Kennedy (Phone attendance)

## Members Absent:

Janelle Lewis (excused)

## Staff in Attendance:

Kristie Allensworth  
Aaron Carruthers  
Mike Clark  
Lucia DaSilva  
Janet Fernandez  
Thomas Hamlett  
Mark Polit

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### 1. Call to Order

Nancy Clyde called the meeting to order at 1:12 p.m.

### 2. Establishment of Quorum

A quorum was established and announced by Nancy Clyde at the opening of the meeting.

### 3. Welcome and Introductions

Those in attendance introduced themselves.

### 4. Public Comments

No public comments were presented.

### 5. Review and Approval of State Plan Committee Minutes (6-23-14 and 7-8-14 meetings)

a. The Committee reviewed the minutes submitted for the meeting of 6-23-14

- 1) Motion to approve as submitted (Sandra Smith)
- 2) Motion seconded (Jonathan Clarkson)
- 3) Motion carried (ayes – 3; nays – 0; abstentions - 2)

b. The Committee reviewed the minutes submitted for the meeting of 7-8-14

- 1) Correction to minutes: Change “*Transportation*” to “*Transition*” in description of Area Board 6 Grant Request – State Plan Goal 6 (Page 8 of the SPC Meeting Packet)
  - 2) Motion to approve as submitted, with correction (Sandra Smith)
  - 3) Motion seconded (Jonathan Clarkson)
  - 4) Motion carried (ayes – 4; nays – 0; abstentions - 1)
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6. Grants from Area Boards 9 and 11

a. The Committee reviewed the first grant proposal:

**Area Board 9:** "Early Start Transition Project"

**Amount Requested:** \$20,000.00

**State Plan Goal - #7:** Children birth to 3 who are at risk of or have a developmental delay and their families receive the early intervention services they need to achieve their potential.

**Project Summary:** The project will provide education and support opportunities to parents of children graduating from California's Early Start Program into special education services, Regional Center children's services and health and other community providers serving children with special needs within Ventura, Santa Barbara, and San Luis Obispo Counties. In partnership with the Early Start-funded Family Resource Centers (FRC) serving the tri-counties, Area Board funding will support the following, in both English and Spanish:

- 1) 2 Early Start Transition Workshops (one in Santa Barbara County, one in San Luis Obispo County)
- 2) 2 Early Start Transition Training of Trainers Workshops for FRC staff (one in Santa Barbara County, one in San Luis Obispo County)
- 3) Early Start Transition Coordinator staff time in Ventura County

**Discussion:** Committee members requested clarification regarding the scope of Program work already funded through DDS, in order to encourage and support innovative programming, additional staffing, and/or special projects through the use of Council funds.

b. After discussion, the Committee moved forward with the grant proposal:

- 1) Motion to recommend approval of the grant, as submitted, pending clarification regarding "*the use of Council monies for program staff*" (Robin Hansen)
- 2) Motion seconded (Sandra Smith)
- 3) Motion carried ( ayes – 4; nays – 0; abstentions - 1)

c. The Committee reviewed the second grant proposal:

**Area Board 11:** "Get Safe's First Responder Training: Enhancing Your Ability to Effectively Respond to Persons with Developmental Disabilities"

**Amount Requested:** \$17,756.00

**State Plan Goal - #4:** Public safety agencies, other first responders and the justice system get information and assistance to be knowledgeable and aware of the needs of individuals with developmental disabilities so they can respond appropriately when individuals with developmental disabilities may have experienced abuse, neglect, sexual or financial exploitation or violation of legal or human rights.

**Project Summary:** The Project will provide highly targeted information, techniques, and tools to help first responders and other professionals more effectively recognize and work with persons with developmental disabilities, especially in emergency situations. Get Safe will provide outreach and training to traditional first responders (e.g. police officers, EMT & fire personnel, district attorneys, criminal justice professionals, doctors, etc.) and any other service professionals (e.g. city employees, community members, etc.) that may have contact with a victim or potential victims. Get safe will conduct fifteen (15) First Responder Training (FRT) sessions in 90-minute presentations within Orange County.

**Discussion:** The Council had previously approved the concept of this grant proposal, pending clarification of the funding amount.

The Council directed the proposal back to the Committee for approval of up to the full requested Project amount of \$17,756.00.

- d. After discussion, the Committee moved forward with the grant proposal:
- 1) Motion to approve the grant for the full amount of \$17,756.00, as submitted (Jonathan Clarkson)
  - 2) Motion seconded (Sandra Smith)
  - 3) Motion carried ( ayes – 4; nays – 0; abstentions - 1)

## 7. 2014 Program Performance Report (PPR) Process

### a. Staff Report

Thomas Hamlett gave the Committee a brief institutional review of the State Plan PPR process, stating that the previous Policy and Planning Specialist (Diana Ramirez) left the State Council as the last (5-year) PPR was due. Thomas Hamlett then took over the responsibilities associated with data collection and reporting to AIDD for the first 2.5 years of the current (2012-2016) State Plan, pending the hiring of a replacement.

DD Suite is a State Plan and annual (Program Performance Review) data reporting tool developed by the Massachusetts State Council and approved and required for individual State Councils' use by the AIDD. This tool tracks federal areas of emphasis, performance measures, and program outcome data and narrative summaries for State Plan goals and objectives. Because of the size and diversity of California, its population and Area Board catchment areas, and the number of State Plan activities, grants, and projects throughout the state, Thomas Hamlett devised an Activity Form (in use with the 13 Area Boards) to uniformly collect output/outcome data and narrative summaries of all work associated with the current State Plan. Activity reports are completed and sent to Headquarters staff for 'processing' in two-month batches. Thomas Hamlett explained that the last five months of data will be 'processed' by Janet Fernandez, the new Planning Analyst, who will then be responsible for collecting/collating all activity quantitative and narrative data for the entire year, summarizing narratives, and grouping data for later transfer to the PPR.

The federal AIDD PPR electronic reporting system will be available for data entry on October 1, 2014, which is a month earlier than former years. All PPRs must first be approved by the full Council or its Executive Committee and submitted by the deadline of December 31, 2014.

Furthermore, presenters during a recent NACDD/ITACC webinar strongly suggested that portions of

the PPR should be filled out by a variety of staff and that (portions of) narrative summaries of program outcomes should be written or, at the very least, reviewed and edited by Council members.

Samples of three different activity (data) reporting tools were then reviewed by the Committee. The reports include activity data collected for the first seven (7) months of this reporting year (October 2013 through April 2014) and broken out by Area Board, goal areas, and/or the types of citizens receiving services (e.g. consumers, family, or others), with breakout figures for dollars leveraged. The reports include activities completed by Area Boards and do not include grant outcome information (current grant projects address emergency planning and/or housing goals) or activities generated by Headquarters staff. The reports are designed and intended to update Committee/Council members on progress toward incremental fulfillment of State Plan goals and objectives.

- b. Carmela Garnica joined the meeting (phone attendance) at 2:15 p.m.
- c. After discussion, the Committee determined that:
  - 1) The data presented in the reporting samples is staff, rather than Committee level, material
  - 2) The Committee prefers a more accessible, graphic or narrative presentation for updates
  - 3) Ideally, narrative descriptions of outcomes provide richer assessment potential than straight activity-based numbers, although current State Plan goals/objectives are designed to be measured and reported quantitatively, rather than qualitatively
  - 4) The MTARS Committee will give further direction (per AIDD and the planned Road Map)
  - 5) The upcoming Comprehensive Review and Assessment (needs assessment) will need to be robust and provide good data for developing the next State Plan goals and objectives
  - 6) The next State Plan will have fewer goals and objectives and will be crafted to enable reporting based on AIDD's performance measures

## 8. State Plan Amendment Process

The Committee chose to defer this agenda item until later in the meeting.

## 9. MTARS Committee Update

### a. Staff Report

Mike Clark reported that he is developing a Road Map to assist with the plan toward accomplishment of the Correction Action Plan (CAP).

**Phase I:** From now through January 1, 2015, the goal is to close out the CAP, pending State Council approval and the implementation of AB 1595 (Chesbro)

**Phase II:** From January 1, 2015 through September 31, 2016, the goal is to wrap up the current State Plan, perform a comprehensive needs assessment, and develop a new State Plan

Mike Clark reported that AIDD is very interested in the Council obtaining consultancy assistance in order to achieve a significant paradigm shift toward strategic capacity-building and systems change and advocacy in the next State Plan, for which there is a strong emphasis in the federal DD Act.

Additionally, AIDD is looking for “*state-wideness*” in developing goals and objectives. According to Mike Clark, the continuing dialogue regarding the need for more detail about money and expenditures may also reduce the reimbursement timeline by AIDD.

Finally, in order to meet the AIDD requirement for “*state-wide-ness*,” AB 1595 (Chesbro) must be passed and signed by the Governor for the Council to have the authority to move forward. Mark Polit reported that AB 1595 has been amended for the last time, approved in the Senate, and must now go to the Assembly for concurrence.

b. After discussion, the Committee determined that:

- 1) The current State Plan contains too many goals and objectives
- 2) The State Plan Committee (SPC) will forward its work to the MTARS Committee, which will then send it forward to the Council for approval

**10. 2014 Program Performance Report (PPR) Process** (Continued from previous discussion)

a. Staff Report

Mark Polit briefly discussed State Plans produced in other states, noting that Allison Cruz wrote Florida’s State Plan, which was acknowledged by AIDD as being compliant with federal guidelines and a good example of all of the components of a State Plan. Tennessee also received a good recommendation, in regard to their State Plan.

**11. State Plan Amendment Process** (Continued from previous discussion)

b. Staff Report

Mark Polit reported that substantial amendments (those involving changes to goals or to objectives that would substantively alter the attached goal) to the State Plan require a 45-day period to hold hearings and collect public comments. Such work would have to be done prior to submitting the proposed changes to AIDD for consideration. The Council is not currently pursuing a change request.

In response to a process question posed by Jonathan Clarkson regarding the process used to create the current State Plan, Thomas Hamlett explained that 4 to 6 stakeholder meetings were held throughout the state, with the Council accepting written comments and Area Boards gathering public input, as well. Taking this body of information, Council staff then drafted the State Plan and submitted it to the Council for final approval.

**12. Plan for Next Meeting**

The Committee agreed to meet again on October 27, 2014, from 1:00 to 4:00 p.m.

**13. Adjournment**

Nancy Clyde adjourned the meeting at 4:00 p.m.



# MTARS UPDATE

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II. ORGANIZATIONAL ADMINISTRATION									
	<i>11.1 Staff</i>	<i>2013 MTARS Finding</i>	<i>Other Key Areas of Concern</i>	<i>Documentation/Evidence of Progress</i>	<i>Comments</i>	<i>Task (CA #1)</i>	<i>When</i>	<i>Who</i>	<i>Done</i>
<b>A</b>	The Director shall hire, supervise, and annually evaluate the staff of the Council. Sec. 125(c)(9)	The Council Director (not the Governor) should hire Council staff and supervise and annually evaluate them. Instead the Council Director submits hiring recommendations to the Governor and the Governor has the final authority to hire two deputy level staff. The Council has the final approval for the hiring of other staff.	N/A	1. Policies and/or procedures (with other documentation as necessary) providing evidence of the Council Directors responsibilities of hiring, supervising and evaluating staff 2. Demonstration of the Director's ability to hire, supervise and annually evaluate the staff of the Council	Sufficient evidence must be provided to adequately meet this finding and be considered for special terms and conditions to be lifted	1. AB 1595. Bylaws 2. ED job description	1. 12/1/14 2. 1/1/15	1. ED, Legal, Council 2. HR	1. No 2. No
III. MEMBERSHIP									
	<i>11.1 Membership policies</i>	<i>2013 MTARS Finding</i>	<i>Other Key Areas of Concern</i>	<i>Documentation/Evidence of Progress</i>	<i>Comments</i>	<i>Task (CA #2, 3)</i>	<i>When</i>	<i>Who</i>	<i>Done</i>
<b>B</b>	Membership recommendations solicited by Governor from a broad range of organizational sources including non-state agency members of the Council. Sec125(b)(1)(B)	The Council's membership nomination and appointment process has been historically inhibited by state bureaucracy. It is unclear if and how membership recommendations are solicited from a broad range of DD/DD organizational sources and non-state agency members of the Council.	N/A	1. Policies and/or procedures (with other documentation as necessary) providing evidence of the Council's membership nomination and appointment process and procedures 2. Direct evidence that the appointment process procedures are being implemented	Sufficient evidence must be provided to adequately meet this finding and be considered for special terms and conditions to be lifted	1. Bylaws 2. Membership Committee meeting minutes, list of organizations on distribution list, recruitment materials	1. 12/1/14 2. 4/1/15	1. ED, Legal, Council 2. ED, Comm	1. No 2. No
<b>C</b>	Members reflect the	The appointment process for obtaining new	N/A	1. Policies and/or procedures (with	Sufficient	1. Bylaws	1. 12/1/14	1. ED.	1. No

Oct 6, 2014 Key: CA= Corrective Action Plan Corrective Action, ED= Executive Director, CDD=Chief Deputy Director, DDP=Deputy Director of Policy and Planning, Comm=Council Committee, TA=Technical Assistance

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state's diverse geographic locations, race, and ethnicity. Sec.125(b)(1)(C)	Council members has hindered compliance with the DD Act. Currently, SCDD's membership composition does not meet the requirements for geographic, racial, and ethnic diversity.		other documentation as necessary) providing evidence of outreach efforts to recruit members that reflect the state's diverse geographic locations, race and ethnicity 2. Direct evidence that the Council's membership reflects the state's diverse geographic locations, race and ethnicity	evidence must be provided to adequately meet this finding and be considered for special terms and conditions to be lifted	2. Demographic analysis of Governor's appointees to the Council	2. 12/1/14	2. HR Legal, Council	2. No
<b>III.1 Membership policies</b>	<b>2013 MTARS Finding</b>	<b>Other Key Areas of Concern</b>	<b>Documentation/Evidence of Progress</b>	<b>Comments</b>	<b>Task (CA #4, 5, 6)</b>	<b>When</b>	<b>Who</b>	<b>Done</b>
<b>D</b> The Council has provisions to rotate membership. Sec.125(b)(2)	Each regional office (i.e. Area Board) representative has to be nominated by the governor. Membership rotation has been historically inhibited by the state's bureaucratic appointment process. For example, one regional office has not had representation on the Council for two years.	N/A	1. Policies and/or procedure with other documentation as necessary) providing evidence of Council provisions to rotate membership 2. Direct evidence that the Council is rotating its members per the Council's policy	Sufficient evidence must be provided to adequately meet this finding and be considered for special terms and conditions to be lifted	1. AB 1595, Bylaws 2. Council roster showing membership and changes for 2015	1. 12/1/14 2. 1/1/16	1. ED, Legal, Council 2. ED	1. No 2. No
<b>E</b> The Council has provisions that allow continuation of membership until a new member is appointed. Sec.125(b)(2)	The Council did not provide evidence of a policy for allowing the continuation of Council membership until a replacement member could be appointed.	N/A	1. Policies and/or procedures (with other documentation as necessary) providing evidence of Council provisions that allow continuation of membership until a new member is appointment 2. Direct evidence that the Council is following its members membership policy	Sufficient evidence must be provided to adequately meet this finding and be considered for terms and conditions status	1. AB 1595, Bylaws 2. Council roster showing membership and changes for 2015	1. 12/1/14 2. 1/1/16	1. ED, Legal, Council 2. ED	1. No 2. No

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<p><b>F</b></p> <p>The Council has a process to notify Governor re: membership and vacancies. Sec. 125(b)(2)</p>	<p>The Council did not provide evidence of a transparent and effective process to notify Governor regarding membership vacancies.</p>	<p>N/A</p>	<p>1. Policies and/or procedures (with other documentation as necessary) providing evidence of appointment process to notify Governor of membership and vacancies 2. Direct evidence of notifying Governor of membership recommendations and vacancies</p>	<p>Sufficient evidence must be provided to adequately meet this finding and be considered for special terms and conditions to be lifted</p>	<p>1. Bylaws, administrative procedure 2. Membership Committee reports to Council</p>	<p>1. 12/1/14 2. 4/1/15</p>	<p>1. ED, Legal, CDD, Council 2. ED, Comm</p>	<p>1. No 2. No</p>	
<b>III.2 Membership requirements</b>									
<p><b>G</b></p> <p>60% of membership represent individuals with DD in the following categories: Sec.125(b)(3); Sec.125(b)(5) 1/3 individuals with DD 1/3 parents and guardians of children with developmental disabilities or immediate relatives of guardians of adults with developmental disabilities, 1/3 combination of an individual with developmental disabilities who resides or previously resided in an institution or an individual with developmental disabilities who currently/previously resided in an institution in the State. Sec.125(b)(6)</p>	<p>Historically the Council has had long term vacancies. Several membership rosters have been submitted since last year and four membership vacancies were filled just prior to the on-site monitoring visit. An updated membership roster is requested as part of the FY14 State Plan Amendment to AIDD to ensure compliance.</p>	<p><b>Other Key Areas of Concern</b></p> <p>1. The Council does not have a standard orientation or mentoring process for the Chair or new members. Council members expressed the need for training on the DD Act, the Council program federal mandate, and organization governance 2. State agency representatives lack understanding of their role at Council meetings. While representatives attend full Council meetings, they do not actively engage with the committees. 3. The review team observed lack of supports for some of the self-advocate members of the Council. The review team could not determine if the events were isolated or an overall issue.</p>	<p><b>Documentation/Evidence of Progress</b></p> <p>1. Since the MTARS visit, documentation of Council compliance with membership composition requirement, standard orientation or mentoring process for Chair and new members, including training in the DD Act, the Council program federal mandate, and organization governance. 2. Direct evidence of state agency representatives understanding their role and actively engaging in Council meetings 3. Direct evidence of supports for engaging self-advocate members of the Council in council meetings and council activities.</p>	<p><b>Comments</b></p> <p>Sufficient evidence must be provided to adequately meet this finding and be considered for special terms and conditions to be lifted</p>	<p><b>Task (CA #7)</b></p> <p>1a. Orientation binder, welcome letter, 1b. Annual Councilmember training 2. Welcome letter for Agency reps 3a. Facilitation Policy 3b. SAAC packets and minutes for 2015, evidence of facilitator attendance for 2015</p>	<p><b>When</b></p> <p>1. 1/1/15 1b. 4/1/15 2. 2/1/15 3a. 1/1/15 3b. 1/1/16</p>	<p><b>Who</b></p> <p>1a. ED, Comm 1b. ED 2. ED 3a. ED, Comm 3b. ED</p>	<p><b>Done</b></p> <p>1a. No 1b. No 2. No 3a. No 3b. No</p>	
<b>IV. PROGRAM ADMINISTRATION</b>									

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	2013 MTRAKS Finding	Other Key Areas of Concern	Documentation/Evidence of Progress	Comments	Task (CA #8)	When	Who	Done
<p><b>H</b></p> <p><i>IV.1. Five Year State Plan</i></p> <p>The plan shall focus on Council efforts to bring about the purpose of this subtitle, by specifying 5-year goals, as developed through data driven strategic planning, for advocacy, capacity building, and systemic change related to the areas of emphasis, to be undertaken by the Council. Sec. 124(c)(4)(A)</p>	<p>There was inadequate evidence that the Council engages in data-driven strategic planning to develop the State Plan and takes the primary role in the planning process. State Plan is the Council's Plan and that activities are undertaken by the Council versus the State Plan being one that is configured by and for the Area Boards. Council is free from state interference in the development of the State Plan. The state's DD agency awarded the Council two contracts: (1) Client Rights Advocacy and (2) Volunteer Advocacy Services. This state supported work is documented in the Goal 2 in the Council's State Plan which states: "local offices provide assistance that include systems navigation, technical assistance, attendance to Individualized Education Plan meetings and assistance with due process".</p> <p>The review team heard more about these two projects during interviews and public forum testimony than any other Council supported activity. While AIDD does not question the merit of the projects and the quality of the work being done by Council staff, it raises serious questions about whether the state is directing the Council's State Plan or whether the Council is developing the State Plan.</p>	<p>N/A</p>	<p>1. Evidence of activities, process and/or procedures (with other documentation as necessary) to develop a 5 year strategic plan that addresses systems change, capacity building and advocacy on a statewide basis</p> <p>2. Direct evidence of process and/or procedures (with other documentation as necessary) for the Council to make data driven decisions and evaluate the progress and impact of state plan implementation</p>	<p>This will require ongoing technical assistance and monitoring into the next state plan cycle (2016-2021) before considering whether to special terms and conditions are lifted</p>	<p>1. The plan to plan. Documentation of public outreach, meetings, surveys, use of available data sources (NCI, ICI, CDER, etc). Copies of staff products submitted to committees and Council to support integration of data and public input. Various other documents showing committee work and council review and revisions of state plan.</p> <p>2. Same as 1</p>	<p>1. 10/1/16</p> <p>2. 10/1/16</p>	<p>1. DDPP, Comm, Council, TA</p> <p>2. DDPP, Comm, Council, TA</p>	<p>1. No</p> <p>2. No</p>

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IV.1. Five Year State Plan	2013 MTARS Finding	Other Key Areas of Concern	Documentation/Evidence of Progress	Comments	Task (CA #9)	When	Who	Done
<p><b>I</b> Plan must include assurances related to:                      ➤ <b>(B) USE OF FUNDS -</b> At the request of any State, a portion of any funds provided to such State under this subtitle for any fiscal year shall be available to pay up to 1/2 (or the entire amount if the Council is the designated State agency) of the expenditures found to be necessary by the Secretary for the proper and efficient exercise of the functions of the designated State agency, except that not more than 5 percent of such funds provided to such State for any fiscal year, or \$50,000, whichever is less, shall be made available for total expenditures for such purpose by the designated State agency                      ➤ <b>(C) STATE FINANCIAL PARTICIPATION—</b> The plan shall provide assurances that there</p>	<p>The Council did not provide adequate evidence that the plan is supported by the assurances in Section 125(c)(5)(B -D) and (K - L).                      Regarding (B) Use of Funds, the review team could not draw any conclusions about the Council based on the information provided about the expenditures for the DSA. It was stated during interviews that:</p> <ul style="list-style-type: none"> <li>The DSA charges the Council an indirect rate for the services it provides.</li> <li>The rate stated by Council staff was in excess of the 5% or \$50,000 limit.</li> <li>Staff did not know the DSA's indirect policy and no written policy were provided.</li> <li>The Council is required to pay the indirect rate. The Council staff stated it does so from two contracts the state awards to the Council.</li> </ul>	<p>1. The DSA plays a vital role supporting the development and implementation of the Council's budget. AIDD highly recommends the Council and DSA enter into a Memorandum of Understanding in support of the Council</p> <p>2. Staff expressed a great need for training to better understand the DD Act, the DD Council's federal mandate to conduct and support advocacy, capacity building, and systemic change on a statewide level.</p>	<p>1. Direct evidence/documentation of MOU between the Council and the DSA in support of the Council</p> <p>2. Direct evidence/documentation of DSA's indirect policy</p> <p>3. Direct evidence that the DSA rates are charged to the Council consistent with documents</p> <p>4. Direct evidence that DSA provided match to the Council</p> <p>5. Policies and procedures (with other documentation as necessary) providing evidence of how the Council addresses Conflict of Interest, particularly findings in the MTARS</p> <p>6. Direct evidence that the Council is following its policy and procedures with regards to conflict of interest</p> <p>7. Policies and/or procedures (with other documentation as necessary) regarding : (a) Council staff carrying out solely the responsibilities duties of the Council as described in the DD Act; (b) training on the DD Act, the DD Council's federal mandate</p>	<p>Sufficient evidence must be provided to adequately meet this finding and be considered for special terms and conditions to be lifted</p>	<p>1. MOU                      2. MOU                      3. DSS Invoices                      4. DSS Invoices                      5. AB 1595, Bylaws                      6. Bylaws, Form 700, Gov't Codes 1090 &amp; 87100                      7. Bylaws                      8. Breakdown of staff by funding source, training materials, staff orientation binder                      9. See A</p>	<p>1. 7/1/15                      2. 7/1/15                      3. 2/1/15                      4. 2/1/15                      5. 12/1/14                      6. 12/1/14                      7. 12/1/14                      8. 7/1/15                      9.</p>	<p>1. Legal                      2. Legal                      3. CDD                      4. CDD                      5. ED                      6. ED, Legal                      7. CDD, Legal, HR                      8. CDD, CCpp, HR                      9. ED,</p>	<p>1. No                      2. No                      3. No                      4. No                      5. No                      6. No                      7. No                      8. No                      9. No</p>

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SCDD – AIDD Compliance Task Chart

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<p>will be reasonable State financial participation in the cost of carrying out the plan</p> <p>➤ (D) CONFLICT OF INTEREST.—The plan shall provide an assurance that no member of such Council will cast a vote on any matter that would provide direct financial benefit to the member or otherwise give the appearance of a conflict of interest.</p> <p>➤ (K) STAFF ASSIGNMENTS.—The plan shall provide assurances that the staff and other personnel of the Council, while working for the Council, will be responsible solely for assisting the Council in carrying out the duties of the Council under this subtitle and will not be assigned duties by the designated State agency, office, or entity of the State.</p>	<p>In regards to (D) Conflict of Interest, the majority of the Council is comprised of non-agency representatives who are Area Board representatives. There are 13 Areas Board representatives on the Council and 7 “at large” members. The Area Board representatives sit on the State Council and on the Advisory Committee to the Area Boards. This dual role presents a conflict of interest and gives the appearance of a conflict of interest. The Council does not have a policy or procedure to address this.</p> <p>In regards to (K) Staff Assignments, it appears that Council staff is carrying out work directed by the state and not necessarily the Council through the state funded Client Rights Advocacy and Volunteer Advocacy Services projects.</p> <p>Through these contracts, Council staff conducts assessments and monitoring in the State’s developmental centers. Providing direct services is outside the purview of the Council’s responsibilities. Furthermore, this work is in support of the two state contracts and therefore directs the work carried out by Council staff located in the regional office. Since it is work created by and for the state, it</p>		<p>to conduct and support advocacy, capacity building, and systemic change on a statewide level; (c) state plan implementation, data collection and analysis; supports to engage self-advocate members in council meetings and activities; (d) standard orientation tools for staff, policy manuals and trainings to learn Council programs and administrative requirements</p> <p>8. Direct evidence that the policies and procedures above are being carried out consistent with the policy</p> <p>9. Direct evidence the Council is functioning free of DSA interference as identified in the MTARS findings</p>	<p>evidence must be provided to adequately meet this finding and be considered for special terms and conditions to be lifted</p>	<p>(Staff), H (Five Year State Plan), and M (Fiscal Requirement )</p>	<p>10/1/16</p>	<p>CDD, DDP, Legal, Comm, Council, TA</p>	
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Oct 6, 2014

Key: CA= Corrective Action Plan Corrective Action, ED= Executive Director, CDL= Chief Deputy Director, DDP= Deputy Director of Policy and Planning, Comm=Council Committee, TA= Technical Assistance

SCDD – AIDD Compliance Task Chart

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<p>➤ (L) <b>NONINTERFERENCE</b> —The plan shall provide assurances that the designated State agency, office, or other agency of the State, will not interfere with the advocacy, capacity building, and systemic change activities, budget, personnel, State Plan development, or plan implementation of the Council, except that the designated State agency shall have the authority necessary to carry out the responsibilities described in section 125(d)(3). Sec. 124(c)(5)</p>	<p>raises questions as to whether the Council staff is assisting the Council or the state.</p> <p>In regards to (L) <i>Noninterference</i>, it is very difficult to conclude whether the Council is free of interference:</p> <ul style="list-style-type: none"> <li>• To avoid duplication, issues related to interference with the budget process are described under <i>VI.1 Fiscal Requirements</i></li> <li>• To avoid duplication, issues related to interference with personnel are described under <i>II.1 Staff</i></li> <li>• To avoid duplication, issues related to interference with State Plan development are described in the Section above <i>IV.1. Five Year State Plan</i>.</li> </ul>						
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SCDD – AIDD Compliance Task Chart

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V. EVALUATION AND REPORTS									
Program Performance Report	2013 MTARS Finding	Other Key Areas of Concern	Documentation/Evidence of Progress	Comments	Task (CA #11)	When	Who	Done	
<b>K</b> The Council annually prepares and transmits to the Secretary a report containing information about the progress made in achieving the goals. The report includes: <ul style="list-style-type: none"> <li>Extent to which each goal of Council was achieved. Sec. 125(c)(7)(A)</li> <li>Description of strategies that contributed to achieving goals. Sec. 125(c)(7)(B)</li> <li>Extent to which each goal was not achieved, describes factors that impeded goal achievement. Sec. 125(c)(7)(C)</li> <li>Separate information on self-advocacy goal. Sec. 125(c)(7)(D)</li> </ul>	Overall the Council's Program Performance Report does not specifically describe how each Area Board is contributing to State Plan implementation. Because there are 13 regional offices implementing different parts of the Council State Plan, it is difficult to determine how State Plan achievement is being measured and evaluated.	N/A	1. Policies and/or procedures (with other documentation as needed) providing evidence for the Council to develop a high quality cohesive and comprehensive PPR as described in the guidance provided by ITACC and AIDD 2. Council evaluation plan submitted in the State Plan 3. Review of PPRs to assess whether the Council is utilizing its evaluation plan	This will require ongoing technical assistance and monitoring into the next state plan cycle (2016-2021) before considering whether to special terms and conditions are lifted	1. Documentation of TA received and products based on TA 2. Evaluation plan	1. 1/1/16 2. 10/1/16	1. DDPP, TA 2. DDPP, Comm, Council, TA 3. DDPP, TA	1. No 2. No 3. No	
<b>L</b> An accounting of the manner in which funds paid to the State for a fiscal year were expended. Sec. 125(c)(7)(G)	The Council presented several documents that detailed different aspects of how the federal allotment is being spent, but overall the review team could not determine how the budget is developed and executed and how expenditure data is calculated.	N/A	1. Policies and/or procedures (with other documentation as necessary) providing evidence of how the Council's budget is developed, executed, and how the expenditure data is calculated 2. Review of fiscal documents to assess whether the Council is following its policies and procedures and federal grant requirements	Sufficient evidence must be provided to adequately meet this finding and be considered for special terms and conditions to be lifted	1. State Accounting Policies, Budget Development Directives 2. Expenditures by Object Code for entire budget	1. 2/1/15 2. 2/1/15	1. CDD 2. CDD	1. No 2. No	

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SCDD – AIDD Compliance Task Chart

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VI. FISCAL									
VI.1 Fiscal Requirements	2013 MTARS Finding	Other Key Areas of Concern	Documentation/Evidence of Progress	Comments	Task (CA #12)	When	Who	Done	
M	Council has authority to prepare, approve, and implement a budget to fund programs, projects, and activities. See 125(c)(8)	The Council did not provide adequate evidence on how it developed or implemented its budget to fund programs, projects, and activities: <ul style="list-style-type: none"> <li>Council members expressed a strong need for more fiscal transparency and training on state versus federal fiscal policy and the Council's budget development/implementation process.</li> <li>The Lanterman Act requires the Council to provide funding to Area Boards.</li> <li>The Lanterman Act provisions require the Council to hire staff at the deputy director level thereby interjecting a line item in the Council's budget and limiting its authority to develop a budget.</li> </ul>	N/A	1. Policies and/or procedures (with other documentation as necessary) providing evidence of how the Council's budget is developed, executed, and how the expenditure data is calculated 2. Policies and/or procedures revised (with other documentation as necessary) as a result of the Lanterman Act 3. Direct evidence that the full Council is developing, approving and managing its budget	Sufficient evidence must be provided to adequately meet this finding and be considered for special terms and conditions to be lifted	1. State Accounting Policies, Budget Development Directives 2. AB 1595 3. Council reviews of Quarterly Budget Projections, Council votes on resource allocation, including cost-reductions	1. 2/1/15 2. 12/1/14 3. 7/1/15	1. CDD 2. ED, Legal 3. ED, CDD, Comm, Council	1. No 2. No 3. No

SCDD – AIDD Compliance Task Chart

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VI.2 Fiscal Policies	2013 MTARS Finding	Other Key Areas of Concern	Documentation/Evidence of Progress	Comments	Task (CA #13)	When	Who	Done
<p>N</p> <p>Council has policies to carry out appropriate subcontracting activities. Sec.125(c)(8)(A)</p> <p>Council directs expenditures of funds for grants, contracts, interagency agreements that are binding contracts and other activities authorized by State Plan approval. Sec.125(c)(8)(C)</p> <p>Grantee shall keep records that disclose:</p> <ul style="list-style-type: none"> <li>• Amount and disposition of assistance by recipient</li> <li>• Total cost of project or undertaking in connection with assistance given</li> <li>• Amount of project costs supplied by other sources</li> <li>• Such other records that will facilitate an effective audit</li> </ul> <p>Sec.103</p>	<p>The Council did not provide adequate evidence of that is has accurate financial accounting and record keeping:</p> <ul style="list-style-type: none"> <li>• At the time of the on-site visit, the Administrative Services Manager position was vacant and the Council did not have a staff person dedicated to managing the Council's finances.</li> <li>• The Council could only provide limited information on the Council's fiscal policies during the on-site visit pertinent to the requirements in the DD Act.</li> <li>• The Council experienced fiscal impropriety under the previous Executive Director (Board Resource contract)</li> <li>• The state auditor's findings substantiate the immediate need for financial management systems. (Reference: <i>California Department of Finance Management Letter dated August 17, 2012</i>)</li> </ul>	<p>N/A</p>	<p>1. Policies and/or procedures (with other documentation as necessary) providing evidence the Council carries out appropriate subcontracting activities, accurate financial accounting and record keeping</p> <p>2. Direct evidence that the Council is following its subcontracting policies</p>	<p>Sufficient evidence must be provided to adequately meet this finding and be considered for special terms and conditions to be lifted</p>	<p>1. Contract Manual</p> <p>2. Signature pages of contracts, routing slips for contract review, meeting minutes for contracts that went to Council for 2015</p>	<p>1. 12/1/14</p> <p>2. 1/1/16</p>	<p>1. CDD</p> <p>2. CDD</p>	<p>1. No</p> <p>2. No</p>

Oct 6, 2014 Key CA= Corrective Action Plan Corrective Action, ED= Executive Director, CDD=Chief Deputy Director, DDPP=Deputy Director of Policy and Planning, Comm=Council Committee, TA=Technical Assistance

SCDD – AIDD Compliance Task Chart

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VII. DESIGNATED STATE AGENCY										
VII.2 Responsibilities of DSA		2013 MTARS Finding		Other Key Areas of Concern	Documentation/Evidence of Progress	Comments	Task (CA #14)	When	Who	Done
<ul style="list-style-type: none"> <li>Receives, accounts for, and disburses funds under subtitle based on State Plan, Sec125(d)(3)(C)(i)</li> <li>Provides the appropriate fiscal control and fund accounting procedures as may be necessary to assure proper disbursement of, and accounting for, funds paid to the state.</li> <li>Keeps and provides access to records as Secretary and Council may determine necessary and timely financial reports regarding status of expenditures, obligations, and liquidation by agency or Council, and use of Federal and non-Federal shares, Sec125(d)(3)(D)</li> <li>Provides required non-Federal share, Sec125(d)(3)(E)</li> <li>Assists in obtaining appropriate State Plan assurances and consistency with state law, Sec125(d)(3)(F)</li> <li>Enters into MOU at request of Council, Sec125(d)(3)(G)</li> </ul>		<p>As mentioned above the Council's recent experience with fiscal improperly under the previous Executive Director (Board Resource contract) and the state auditor's findings substantiates the DSA's need to establish processes, policies, and procedures that promote:</p> <ul style="list-style-type: none"> <li>Accurate receipt, accounting, and disbursement of funds</li> <li>Provision of appropriate fiscal control and fund accounting procedures necessary to assure proper disbursement of, and accounting for, funds paid</li> <li>Access to records as the Secretary and Council may determine necessary</li> <li>Timely development and dissemination of financial reports regarding status of expenditures, obligations, and liquidation by agency or Council, and use of Federal and non-Federal shares</li> </ul>		N/A	<p>1. Policies and/or procedures (with other documentation as necessary) providing evidence the DSA has promoted: Accurate receipt, accounting, and disbursement of funds; Provision of appropriate fiscal control and fund accounting procedures necessary to assure proper disbursement of, and accounting for, funds paid; Access to records as the Secretary and Council may determine necessary; and timely development and dissemination of financial reports regarding status of expenditures, obligations, and liquidation by agency or Council, and use of Federal and non-Federal shares</p>	<p>Sufficient evidence must be provided to adequately meet this finding and be considered for special terms and conditions to be lifted</p>	<p>1. State accounting policies</p> <p>2. DSA Annual Evaluation (possibly GalSTARS reports)</p>	<p>1. 2/1/15</p> <p>2. 7/1/15</p>	<p>1. CDD, Legal</p> <p>2. CDD, Comm</p>	<p>1. No</p> <p>2. No</p>
<p>Several Council staff position and DSA functions appear duplicative. Several DSA functions are performed by Council staff at the central office, specifically in the areas of: contracting, budget, fiscal, and personnel.</p>		<p>There was no evidence that the Council has conducted a formal evaluation of the DSA at any point and time.</p>			<p>2. Direct evidence that the DSA is carrying out the policies and procedures</p>					

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## AIDD Compliance Task Timeline

Date Due	Item No.	Task Description	Documentation/Evidence of Progress	Who
December 1, 2014	A1.	AB 1595, Bylaws	Policies and/or procedures (with other documentation as necessary) providing evidence of the Council Directors responsibilities of hiring, supervising and evaluating staff	E.D. Legal Council
December 1, 2014	B1.	Bylaws	Policies and/or procedures (with other documentation as necessary) providing evidence of the Council's membership nomination and appointment process and procedures	E.D. Legal Council
December 1, 2014	C1.	Bylaws	Policies and/or procedures (with other documentation as necessary) providing evidence of outreach efforts to recruit members that reflect the state's diverse geographic locations, race and ethnicity	E.D. Legal Council
December 1, 2014	C2.	Demographic analysis of Governor's appointees to the Council	Direct evidence that the Council's membership reflects the state's diverse geographic locations, race and ethnicity	H.R.
December 1, 2014	D1.	AB 1595, Bylaws	Policies and/or procedure with other documentation as necessary providing evidence of Council provisions to rotate membership	E.D. Legal Council
December 1, 2014	E1.	AB 1595, Bylaws	Policies and/or procedures (with other documentation as necessary) providing evidence of Council provisions that allow continuation of membership until a new member is appointment	E.D. Legal Council
December 1, 2014	F1.	Bylaws, administrative procedure	Policies and/or procedures (with other documentation as necessary) providing evidence of appointment process to notify Governor of membership and vacancies	E.D. Legal C.D.D. Council
December 1, 2014	I5.	AB 1595, Bylaws	Policies and procedures (with other documentation as necessary) providing evidence of how the Council addresses Conflict of Interest, particularly findings in the MTARS	E.D.
December 1, 2014	I6.	Bylaws, Form 700, Gov't Codes 1090 and 87100	Direct evidence that the Council is following its policy and procedures with regards to conflict of interest	E.D. Legal

## AIDD Compliance Task Timeline

Date Due	Item No.	Task Description	Documentation/Evidence of Progress	Who
December 1, 2014	17.	Bylaws	Policies and/or procedures (with other documentation as necessary) regarding : (a) Council staff carrying out solely the responsibilities duties of the Council as described in the DD Act; (b) training on the DD Act, the DD Council's federal mandate to conduct and support advocacy, capacity building, and systemic change on a statewide level; (c) state plan implementation, data collection and analysis, supports to engage self-advocate members in council meetings and activities; (d) standard orientation tools for staff, policy manuals and trainings to learn Council programs and administrative requirements	CDD Legal HR
December 1, 2014	M2.	AB 1595	Policies and/or procedures revised (with other documentation as necessary) as a result of the Lanterman Act	ED Legal
December 1, 2014	N1.	Contract Manual	Policies and/or procedures (with other documentation as necessary) providing evidence the Council carries out appropriate subcontracting activities, accurate financial accounting and record keeping	CDD
January 1, 2015	A2.	Executive Director job description	Demonstration of the Director's ability to hire, supervise and annually evaluate the staff of the Council	H.R.
January 1, 2015	G1a.	Orientation binder, welcome letter	Since the MTARS visit, documentation of Council compliance with membership composition requirement, standard orientation or	E.D.
January 1, 2015	G3a.	Facilitation Policy	Direct evidence of supports for engaging self-advocate members of the Council in council meetings and council activities.	E.D.
February 1, 2015	G2.	Welcome letter for agency reps	Direct evidence of state agency representatives understanding their role and actively engaging in Council meetings	E.D.
February 1, 2015	13.	DSS Invoices	Direct evidence that the DSA rates are charged to the Council consistent with documents	CDD
February 1, 2015	14.	DSS Invoices	Direct evidence that DSA provided match to the Council.	CDD

## AIDD Compliance Task Timeline

Date Due	Item No.	Task Description	Documentation/Evidence of Progress	Who
February 1, 2015	L1.	State accounting policies, budget development directives	Policies and/or procedures (with other documentation as necessary) providing evidence of how the Council's budget is developed, executed, and how the expenditure data is calculated	CDD
February 1, 2015	L2.	Month's expenditures by object code for entire budget	Review of fiscal documents to assess whether the Council is following its policies and procedures and federal grant requirements	CDD
February 1, 2015	M1.	State accounting policies, budget development directives	Policies and/or procedures (with other documentation as necessary) providing evidence of how the Council's budget is developed, executed, and how the expenditure data is calculated	CDD
February 1, 2015	O1.	State accounting policies	Policies and/or procedures (with other documentation as necessary) providing evidence the DSA has promoted: Accurate receipt, accounting, and disbursement of funds; Provision of appropriate fiscal control and fund accounting procedures necessary to assure proper disbursement of, and accounting for, funds paid; Access to records as the Secretary and Council may determine necessary; and timely development and dissemination of financial reports regarding status of expenditures, obligations, and liquidation by agency or Council, and use of Federal and non-Federal shares	CDD Legal
April 1, 2015	B2.	Membership Committee meeting minutes, list of	Direct evidence that the appointment process procedures are being implemented.	E.D. Committee
April 1, 2015	F2.	Membership Committee reports to Council	Direct evidence of notifying Governor of membership recommendations and vacancies	E.D. Committee
April 1, 2015	G1b.	Annual Councilmember training	Since the MTARS visit, documentation of Council compliance with membership composition requirement, standard orientation or	E.D.
July 1, 2015	I1.	MOU	Direct evidence/documentation of MOU between the Council and the Legal DSA in support of the Council	Legal
July 1, 2015	I2.	MOU	Direct evidence/documentation of DSA's indirect policy	Legal

## AIDD Compliance Task Timeline

Date Due	Item No.	Task Description	Documentation/Evidence of Progress	Who
July 1, 2015	18.	Breakdown of staff by funding source, training materials, staff orientation binder	Direct evidence that the policies and procedures above are being carried out consistent with the policy	CDD CCPP HR
July 1, 2015	J1b.	Evidence of periodic meetings and joint activities.	Policies and/or procedures (with other documentation as needed) providing evidence of how the Council will develop and address state plan goals on a statewide basis; plans for collaboration with the DD Network Partners	ED
July 1, 2015	M3.	Council reviews of monthly budget projections, Council votes on resource allocation, including cost-reductions	Direct evidence that the full Council is developing, approving and managing its budget	ED CDD Committee Council
July 1, 2015	O2.	DSA Annual Evaluation (possibly CalSTARS report)	Direct evidence that the DSA is carrying out the policies and procedures.	CDD, Comm
September 1, 2015	J1a.	State Plan work plan	Policies and/or procedures (with other documentation as needed) providing evidence of how the Council will develop and address state	ED DDP
January 1, 2016	D2.	Council roster showing membership and changes for 2015	Direct evidence that the Council is rotating its members per the Council's policy	E.D.
January 1, 2016	E2.	Council roster showing membership and changes for 2015	Direct evidence that the Council is following its members membership policy	E.D.
January 1, 2016	G3b.	SAAC packets and minutes for 2015, evidence of facilitator attendance for 2015	Direct evidence of supports for engaging self-advocate members of the Council in council meetings and council activities.	E.D.
January 1, 2016	J2.	Amended plan and supporting documentation.	For the remainder of the 2011-2016 state plan, evidence of amended and implemented goals on a statewide basis.	DDPP Committee Council TA

## AIDD Compliance Task Timeline

Date Due	Item No.	Task Description	Documentation/Evidence of Progress	Who
January 1, 2016	K1.	Documentation of TA received and products based on TA	Policies and/or procedures (with other documentation as needed) providing evidence for the Council to develop a high quality cohesive and comprehensive PPR as described in the guidance provided by ITACC and AIDD	DDPP TA
January 1, 2016	N2.	Signature pages of contracts, routing slips for contract review, meeting minutes for contracts that went to Council for 2015	Direct evidence that the Council is following its subcontracting policies.	CDD
October 1, 2016	H1.	The plan to plan. Documentation of public outreach, meetings, surveys, use of available data sources (NCI, ICI, CDER, etc). Copies of staff products submitted to committees and Council to support integration of data and public input. Various other documents showing committee work and council review and revisions of state plan.	Evidence of activities, process and/or procedures (with other documentation as necessary) to develop a 5 year strategic plan that addresses systems change, capacity building and advocacy on a statewide basis	DDPP Committee Council Technical Assistance

## AIDD Compliance Task Timeline

Date Due	Item No.	Task Description	Documentation/Evidence of Progress	Who
October 1, 2016	H2.	The plan to plan. Documentation of public outreach, meetings, surveys, use of available data sources (NCL, ICI, CDER, etc). Copies of staff products submitted to committees and Council to support integration of data and public input. Various other documents showing committee work and council review and revisions of state plan.	Direct evidence of process and/or procedures (with other documentation as necessary) for the Council to make data driven decisions and evaluate the progress and impact of state plan implementation	DDPP Committee Council Technical Assistance
October 1, 2016	I9.	See A (Staff), H (Five Year State Plan), and M (Fiscal Requirement)	Direct evidence the Council is functioning free of DSA interference as identified in the MTARS findings	ED CDD DDPP Legal Committee Council TA
October 1, 2016	K2.	Evaluation plan	Council evaluation plan submitted in the State Plan.	DDPP Committee Council TA
January 1, 2017	J3.	Approval of new state plan	Approval of new state plan for FY 2016-2021	DDPP Committee Council TA

## AIDD Compliance Task Timeline

Date Due	<u>Item No.</u>	<u>Task Description</u>	<u>Documentation/Evidence of Progress</u>	<u>Who</u>
January 1, 2018	J4.	PPR	Review of PPRs to assess the extent to which the Council is conducting and supporting advocacy, capacity building and systemic change activities consistent with the DD Act	DDPP Committee Council TA
January 1, 2018	K3.	PPR	Review of PPRs to assess whether the Council is utilizing its evaluation plan	DDPP TA



# PPR REPORTING FORMAT



## Regional Office Activity Form

<b>Activity / Staff Contact:</b>		<b>Contact Phone Number:</b>	<b>Date of Activity:</b>	
<b>Regional Office:</b> Choose office:	<b>Reporting Period:</b> Choose month:	<b>Project Name:</b>		
<b>Primary Strategy:</b> Choose one:		<b>Federal Area of Emphasis:</b> Choose one:		
<b>Project Objective:</b> Choose one:		<b>Funds Leveraged:</b>		
<b>Collaborators:</b> <input type="checkbox"/> University Center of Excellence <input type="checkbox"/> Disability Rights California <input type="checkbox"/> DDS <b>Others:</b>				
<b>Attachments (Personal Stories, Surveys, Flyers/Handouts, etc.)</b> <input type="checkbox"/> Yes <input type="checkbox"/> No				
<b>Narrative of Activity:</b>				
<b>Personal Stories (legislation, policies, lives changed or made better):</b>				
<b>Emerging Issues\Barriers to Implementation:</b>				
<b>How did you evaluate these activities? What were the results?</b>				
<b>Performance Measure:</b>		<b>SA</b>	<b>FA</b>	<b>Other</b>
Choose one:				
<b>Performance Measure:</b>		<b>SA</b>	<b>FA</b>	<b>Other</b>
Choose one:				
<b>Performance Measure:</b>		<b>SA</b>	<b>FA</b>	<b>Other</b>
Choose one:				33

**Narrative (continued):**

**Personal stories (continued):**

**Emerging Issues\Barriers (continued):**

**Activity Evaluation (continued):**

# STATE PLAN TIMELINE



## 2016-5-Year State Plan: Tentative/Proposed Development Timeline

Start Date	Task	Responsible Parties	Finish Date
October 2014	<b>Comprehensive Review Analysis:</b>	Council SPC All Staff	January 2016
October 2014	1. Identify/assemble list of potential data sources to determine statewide needs (e.g. NCI, activity reports, QA results, previous PPRs, town hall meetings/public input/testimony/surveys, etc.)	All Staff SPC Council	November 2014
November 2014	2. Collect data from identified/other sources	Council All Staff	March 2015
April 2015	3. Assemble data into <i>Comprehensive Review Analysis</i> format	HQ Staff	July 2015
July 2015	4. Review CRA results with ITACC & AIDD 5. Revise, as necessary	HQ Staff	August 2015
August 2015	6. Review CRA 7. Submit to Council for review/approval	HQ Staff SPC	September 2015
September 2015	8. Review/approve CRA	Council	September 2015
September 2015	<b>Development of 5-yr State Plan</b>	SPC & Council HQ Staff	July 2016
September 2015	1. Develop 5 broad Goals & 10 specific, measurable Objectives 2. Review for measurability (based on federal criteria) 3. Submit proposed Goals/Objectives to Council	SPC HQ Staff	December 2016
December 2016	4. Review proposed Goals/Objectives 5. Provisional approval, pending public review/comments	Council	January 2016
January 20 2016	6. Public Comment Period (e.g. website, town hall meetings, etc.)	All Staff Council	March 2016
March 2016	7. Proposed revisions developed, based on public input 8. Review measurability of Goals/Objectives w/ AIDD/ITACC 9. Submit revised State Plan Goals/Objectives to Council	SPC HQ Staff	May 2016
May 2016	10. Approve final set of State Plan Goals/Objectives	Council	May 2016
April 2016	11. Complete final State Plan draft 12. Submit to SPC for final review/approval	HQ Staff SPC	June 2016
June 2016	13. Submit full 5-yr State Plan to Council for final review/approval	SPC Council	July 2016
July 2016	14. Submit full 5-yr State Plan to AIDD, via DD Suite 15. Establish statewide work plan & submit to Council for review	HQ Staff	August 15 2016
August 2016	16. State Plan review/approval of work plan	AIDD	September 2016
September 2016	17. Execute revisions to 5-yr State Plan, as necessary (AIDD Revisions) 18. Convert 5-yr State Plan to plain language & disseminate (e.g. website, emailing, newsletters, etc.) 19. Clarify activities & reporting requirements w/ Area staff	HQ Staff SPC	October 2016
October 2016	<b>Implementation of 5-yr State Plan</b>	All Staff	September 2021
November 2016	1. Review of October monthly activities – Cumulative Report	Council	November 2016



**2016 5-yr State Plan  
Tentative/Proposed Development Timeline**

Timeline	2014			2015												2016			2017		
	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec	Jan	Feb	Mar			
All Staff SPC Council	1. Identify & assemble list of potential data sources to determine statewide needs (e.g. NCI, activity reports, QA results, previous PPRs, town hall meetings/public input/testimony/surveys, etc.)																				
Council All Staff	2. Collect data from identified/other sources																				
HQ Staff	3. Assemble data into Comprehensive Review Analysis format																				
HQ Staff	4. Review CRA results with ITACC & AIDD																				
HQ Staff SPC	5. Revise, as necessary																				
Council	6. Review CRA																				
SPC & Council	7. Submit to Council for review/approval																				
SPC HQ Staff	8. Review & approve CRA																				
Council	Development of 5-yr State Plan																				
SPC HQ Staff	1. Develop 5 broad Goals & 10 specific, measurable Objectives																				
Council	2. Review for measurability (based on federal criteria)																				
	3. Submit proposed Goals/Objectives to Council																				
	4. Review proposed Goals & Objectives																				
	5. Provisional approval, pending public review & comments																				







# EXAMPLES OF OTHER STATE PLANS





## Five-Year Plan 2012-2016 Goals and Objectives

**Goal 1:** Promote and support the development of leadership and self-advocacy capacity among people with disabilities and their family members.

*Objective 1:* Support leadership training by people with developmental disabilities and their family members for other people with developmental disabilities and their family members who may become leaders in Colorado.

*Objective 2:* Promote and support the development of leadership, self-determination and self-advocacy capacity among people with developmental disabilities and their family members through a variety of strategies, including state-of-the-art technology.

*Objective 3:* Support policy-making groups to actively include people with developmental disabilities and family members in decision-making processes.

*Objective 4:* Serve as a representative voice of the cultural competence and cultural diversity interests and concerns among Colorado citizens with developmental disabilities.

*Objective 5:* Support and expand participation of people with developmental disabilities in cross-disability and culturally diverse leadership coalitions.

*Objective 6:* Establish or strengthen a program for the direct funding of a State self-advocacy organization led by people with developmental disabilities.

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**Goal 2:** Support the development of broad community coalitions that include people with developmental disabilities in natural proportions to address community-identified issues.

*Objective 1:* Support local grassroots efforts in Colorado communities, with emphasis on rural areas, to contribute to the development of such efforts as accessible transportation, affordable housing, employment, inclusive recreation or meaningful participation in community policies that expand access and inclusion.

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**Goal 3:** People with developmental disabilities will be free from abuse, neglect, exploitation, seclusion and restraint related to differential treatment because of disability in any settings.

*Objective 1:* The Council will investigate and establish an effective means for ongoing monitoring of the frequency with which people who have developmental disabilities experience instances of abuse, neglect, exploitation, seclusion and restraint.

*Objective 2:* The Council will work to implement successful strategies to decrease and ultimately prevent instances in which people with developmental disabilities experience abuse, neglect, exploitation, seclusion or restraint.

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**Goal 4:** Support and sustain community inclusion of people with developmental disabilities in real jobs that offer real wages where non-disabled community members work.

*Objective 1:* Participate in and support a network of agencies providing education, training, employment and other supports to employers, community members and people with disabilities.

*Objective 2:* Support the cultivation of natural supports within non-segregated employment settings that foster job retention, skill achievement/enhancement and employee success.

*Objective 3:* Promote and increase the active participation of people with developmental disabilities in designing the approach and implementation of employment strategies.

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**Goal 5:** Improve the quality of life, and increase real choices for people with disabilities to live in their communities by providing them the resources they need to live a quality inclusive life.

*Objective 1:* Support or lead a collaborative approach to the development of a long-term strategic plan to increase public awareness and understanding of the gifts and abilities of people with developmental disabilities in Colorado, both those receiving services and those on waiting lists, as well as the supports they need to be contributing members of their communities.

*Objective 2:* Engage in public policy and advocacy activities that encourage and result in the simplification and coordination of systems and resources for the support of people with developmental disabilities.



## **FIVE YEAR STATE PLAN FOR FFYs 2012-2016**

### **SECTION I: COUNCIL IDENTIFICATION**

The Minnesota Governor's Council on Developmental Disabilities (GCDD) was established on October 28, 1971. The GCDD is authorized under Minnesota Statute 16B.054 and 16B.055. Colleen Wieck is the Executive Director.

State Plan period: October 1, 2011 through September 30, 2016.

Membership Rotation Plan: The GCDD is composed of 25 members appointed for three-year terms with a maximum of two consecutive terms. Each member is appointed by the Governor from among state residents. The GCDD members represent the Departments of Education; Employment and Economic Development, and Human Services; the Institute on Community Integration (University Center for Excellence) and the Minnesota Disability Law Center (Protection and Advocacy system). Nongovernmental agencies and private nonprofit organizations are also represented.

#### **Current GCDD Members:**

Anne Barnwell  
Roberta Blomster  
Peg Booth  
Jennifer Giesen  
Brian Gustafson  
Anne Hennessey  
Shawn Holmes  
Tom Holtgrewe  
Loraine Jensen  
Matt Kamer  
Susan Kratzke  
Steve Kuntz  
Louis Lenzmeier  
Stevie K. Nelson  
Derek Nord  
Marisa Novak  
Linda Obright  
Jeff Pearson, Chair  
Dan Reed  
Connie Roy  
Bryan Schmidt  
Barbara Schultz  
Stacey Vogeles  
Wendy Wangen  
Susan Wehrenberg

## **SECTION II: DESIGNATED STATE AGENCY**

The Designated State Agency (DSA) for the GCDD is the Minnesota Department of Administration. The DSA was designated in 1991. Spencer Cronk is the Commissioner of the Department.

The GCDD does not provide or pay for direct services to persons with developmental disabilities. The GCDD does not have a Memorandum of Understanding with the DSA.

Roles and Responsibilities of the DSA related to the GCDD: The Minnesota Department of Administration is one of the oldest state agencies. Its mission is to help customers succeed. It has a wide range of activities that serve citizens and state government.

As the DSA, the Department of Administration provides administrative services for the GCDD including financial management and reporting, human resources, information technology support, disaster recovery planning, real estate management services, risk management insurance, and overall supervision and support services.

### **SECTION III: COMPREHENSIVE REVIEW AND ANALYSIS**

#### **Introduction:**

The Five Year State Plan process was presented at the October 6, 2010 Council meeting. Key actions were taken at each Council meeting in order to meet deadlines.

A statewide survey of individuals with developmental disabilities and their families was recently conducted to identify important issues to be addressed, and how and where services and delivery systems can make improvements over the next five years. The survey also measured levels of independence, productivity, self determination, integration and inclusion among people with developmental disabilities as was done in 2000 and 2005.

A statewide Survey of Providers was also conducted to learn their opinions about a range of issues including employment, recreation, self advocacy, health, quality assurance, housing, education, early intervention, and child care. There are about 200 service providers in Minnesota; 66 service providers completed this survey.

Survey results and a meta-analysis of all research studies conducted over the past 10 years were presented at the December 1, 2010 GCDD meeting. From January through June, GCDD staff reviewed hundreds of documents and studies to prepare for this Comprehensive Review.

At a regular GCDD meeting on February 2, 2011, the Grant Review Committee (GRC) reviewed and provided feedback on goal statements that reflected the survey results. All goals were approved by the Council pending a public review and comment process. Following the Council meeting, proposed goal statements were sent to all Council members for their review and comment, and any additional ideas.

The proposed goal statements were posted on the Council website on February 18, 2011 and also directed to the Protection and Advocacy agency, University Center for Excellence, providers, self advocates, grant recipients, and key stakeholders. Partners in Policymaking graduates were also asked for their input, and to invite comments and feedback from individuals in their respective networks.

A total of 64 responses were received; substantive comments and refinements were added to the goal statements. Any other comments will be held until RFPs are developed so that ideas and input can be incorporated. At a regular GCDD meeting on April 6, 2011, the revised goal statements were again reviewed by the GRC along with proposed objectives and performance targets for each of the five State Plan years. The objectives and performance targets were based in

part on a review of business results from the past five years. The GCDD approved the goals at the April meeting.

## **PART A. State Information**

### **(i) Racial and Ethnic Diversity:**

The racial and ethnic diversity of the state population is noted with primary groups represented as a percentage of the state's population based on the 2010 Census. In terms of race statewide, nonwhites and Hispanics account for 17% of the population, up from 12% in 2000. Minorities account for nearly 25% of the population in the seven county metropolitan area, up from 17% in 2000.

### **(ii) Poverty Rate:** The poverty rate is 10.9%.

### **(iii) State disability characteristics/prevalence rate:**

The Gollay National Prevalence Rate establishes the rate of developmental disabilities occurring in the population at 1.8%. According to the 2010 Census, Minnesota's population is 5,303,925. Using Gollay, it is estimated that there are 95,471 people with developmental disabilities in Minnesota.

## **PART B. Portrait of State Services**

### **(i) Health/Health Care:**

**Medical Assistance:** Minnesota has been a consistent leader in promoting and implementing initiatives that improve access, quality, and cost-effectiveness of services provided through publicly funded health care programs. These combined efforts have improved access to health care for low income, special need, and uninsured Minnesotans. At the same time, program eligibility requirements have become more complex.

Health care services are provided by managed care organizations for those who are 65 years or older. For those under age 65, services are provided on a fee for service basis except for home health care and rehabilitative services provided under a Prepaid Medical Assistance program. There are special needs basic care options available for people with disabilities between the ages of 18 and 64 years.

**In FY 2009**, approximately 707,000 Minnesotans were enrolled in publicly funded health care programs. Of that number approximately 100,000 Minnesotans with disabilities were enrolled in the state Medicaid program.

Passage of federal health care reforms has created new complexities including the need to modify state policies regarding payments and program integrity, expansion of eligibility, etc.

The Legislature is currently reviewing all aspects of Minnesota health care programs.

In July 2010, Minnesota completed a Title V Block Grant Needs Assessment, a comprehensive review of maternal and child health care: Pregnant women/infants: In 2008, there were 1,048,477 women of normal childbearing age between 15 and 44 years old, and a total of 84,653 pregnancies including 114 pregnant females under the age of 15. The age specific pregnancy rate was 80.7 per 1000 females. The number of low birth weight infants has declined slightly from 6.8 percent to 6.4 percent in 2008.

Children and Youth with Special Health Care Needs (CYSCHCN): Approximately 14.4 percent of the total state population may be in need of special health care services. In 2008, a total of 180,669 children were in need of services. Males are more likely to need services than females. The highest proportion of children in need are African American while Asian and Spanish Speaking Hispanic community members have the lowest percentage. Children of all races with disabilities are evenly spread across all poverty levels.

Mental Health for Children/Adults: Approximately 35,000 people receive publicly funded substance abuse treatment services; 187,000 adults and approximately 48,000 children receive publicly funded mental health services. Children's mental health services are measured by service penetration rate and number of children receiving any type of mental health service. In CY 2008, the rate was 342 per 10,000 children, compared with 341 per 10,000 children in CY 2007, and 334 per 10,000 children in CYs 2005 and 2006.

Institutional Care: The use of Medicaid funded rehabilitative services, personal care, and the home and community based waiver has helped reduce reliance on Regional Treatment Centers. The last resident with developmental disabilities left the state hospital system in 2000.

Comprehensive Health/Mental Health: In terms of mental health rehabilitative services, Minnesota provides several community mental health services in order to direct the mental health system toward

individualized services and recovery. Rehabilitative services have been added and include adult rehabilitative mental health services, assertive community treatment, intensive residential treatment services, children's therapeutic services and supports, and preferred integrated networks.

Public/Private Insurance Access: The State Health Access Data Assistance Center helps states monitor and understand trends in rates of health insurance coverage and, in 2009, Minnesota compared with the United States overall:

Minnesotans with health insurance - 90.9 percent; US – 84.6 percent.

Minnesota workers employed by businesses that offered health insurance – 88.1 percent; US – 87.6 percent.

Minnesotans eligible for employer health insurance – 79.4 percent; US – 79.5 percent.

Medicaid enrollment in MN as percent of population under 200 percent FPL – 46.8 percent; US – 45.6 percent.

Prevention and Wellness: Local public health programs provide infant, child, and adolescent growth and development services, assistance with pregnancy and birth, injury prevention, nutrition programs, family home visits, immunization clinics, follow-along programs, and WIC clinics.

Regarding hearing screening, every child with a hearing loss receives a call from a parent who has a child with a hearing loss. Parent guides are provided through Minnesota Hands and Voices.

Regarding newborn screening, the Newborn Blood Spot Screening Program tests samples taken from newborns, notifies the doctor and tracks any testing, as well as links families to resources.

**(ii) Employment:**

Job Training, Job Placements, and Vocational Rehabilitation Services (VRS): The VRS program is a federal-state partnership currently funded at \$58 million. For every state dollar, the federal match is \$3.71. Minnesota does not draw down as much federal money as it could because of the lack of a state match. An additional complication for the Minnesota program is the dwindling amount of carry forward funds. According to the 2011 Minnesota State Rehabilitation Council Annual Report, the VRS program reported over 2,000 competitive placements; the

top areas of competitive employment placements were service jobs, clerical and sales, professional/technical, industry, and health care. On federal performance measures, Minnesota met standards except in terms of (a) the number of people with disabilities employed compared to the previous year and (b) the wages of those placed by VRS compared to state wages. Minnesota has implemented an "order of selection" methodology and people with developmental disabilities would be included in those with the most significant disabilities.

Worksite Accommodations: The GCDD conducted three studies of Minnesota employers and documented worksite accommodations, both physical and programmatic accommodations. The majority of employers reported the cost of accommodations were equal to or less than they anticipated and benefits outweighed costs.

Work Incentives/Benefits – MA/EPD: Minnesota began a Medicaid buy-in program in 1999, the program is called Medical Assistance for Employed People with Disabilities (MA-EPD). The minimum monthly income is \$65.00 and there is no upper income limit. An eligible person can have a maximum of \$20,000 in assets. Across the years, from 1999 until 2008, there were 19,096 individuals enrolled in MAEPD. There are 1,300 individuals who enroll per year. The total amount of funds raised from premiums was approximately \$5 million (annually). The Work Incentives Connection offers benefits counseling.

School to Work: In terms of transition services, The Minnesota Department of Education (MDE) has several resources available to individuals and families, including Project C3, Connecting Youth to Communities and Careers, the University of Minnesota Reintegration Framework and Systems Planning Toolkit, the National Collaborative on Workforce and Disability, and the National Center on Secondary Education and Transition. The MDE has several performance measures related to transition.

Employment continues to be a major issue for youth in transition. The National Center for Special Education Research conducted two longitudinal studies 15 years apart for students in transition. The most recent results released in 2011 concluded that students with the most significant disabilities are likely to be segregated rather than included in general education classes. Often those with the most significant disabilities received instruction from a paraprofessional and were more likely to go on field trips. Testing results showed the greatest disparities with only one percent of the students with developmental disabilities scoring above the norm.

Competitive Integrated Employment, Sheltered Employment, Data About Employment: In 2009, the total number of people served in Minnesota community-based day and employment programs totaled 13,007; of that number, 18 percent, or 2,341 individuals, were working in integrated settings; a total of 2,288 individuals were in supported employment; the remainder were in segregated employment. Of those individuals with developmental disabilities who received VR services, the rate of closures into employment was 53%; average weekly earnings were \$234 and average weekly hours worked was 26

Total expenditures in 2009 totaled over \$203 million; the majority of funding, \$190 million, came from Medical Assistance. Of the total amount, over \$4.6 million was spent on integrated employment and the remainder was spent on segregated services.

Extended Employment: In 2010, a total of 2,859 individuals with developmental disabilities were receiving services from the VRS program. These individuals represented 13% of the VRS caseload, and 14% of total placements.

**(iii) Informal and Formal Services and Supports:**

Social Services: Minnesota has a state supervised county administered social service system. The Department of Human Services (DHS) is the primary supervisory state agency and there are 87 counties through which services are administered. To seek assistance, people must apply through their local county social service agency. There is a wide range of social services, income support, health care, and long term services available. Case management is a critical issue and several studies call for greater choices and better training of case managers.

Child Welfare: In 2010, the DHS announced that one in four children who were in foster care and returned to their families reentered foster care within 12 months of family reunification. This 24 percent reentry rate was among the worst in the nation. Disability status is the 7<sup>th</sup> most frequent reason for foster care placement and a risk factor for reentry.

Aging: The DHS contracted with Thomson Reuters to prepare a profile of services for people who are aging or have disabilities. The final report is 83 pages and can be found at [http://www.dhs.state.mn.us/main/groups/aging/documents/pub/dhs16\\_144888.pdf](http://www.dhs.state.mn.us/main/groups/aging/documents/pub/dhs16_144888.pdf)

The Minnesota Medicaid program spent \$3.3 billion in State Fiscal Year 2008 on long term supports for older adults, people with disabilities, and

people with serious mental illness or severe emotional disturbances. Since 2004, use of institutional services has decreased while utilization of community services has increased.

Independent Living and Other Services: Personal care assistance (PCA) is a home care service administered by the Minnesota DHS. Between January 1, 2010 and December 10, 2010, PCA services were authorized for 21,408 fee-for-service recipients. There are currently 786 personal care provider organizations that offer traditional PCA services and 500 of those are also PCA Choice agencies that serve as fiscal intermediaries for recipients. As of December 31, 2010, there are 66,490 enrolled personal care assistants.

Family Support: Minnesota offers both consumer support and family support grants to thousands of individuals and families.

Day Training and Habilitation Services: These services are licensed to serve adults with developmental disabilities to improve and maintain independence, enhance personal skills, empower choice making, and improve integration into the community. Services include vocational supports, supported employment, and non vocational supports. Medicaid pays for day training and habilitation through the waiver and ICF level of care. Counties fund services for individuals who are not Medicaid eligible.

Peer Support: The Centers for Independent Living provide peer support as part of their core services.

Faith-based: In September 2003, the GCDD received a Project of National Significance Family Support 360 planning grant and five years of implementation funding. The 360 Center was located in the most unserved/underserved neighborhood in north Minneapolis in a faith based location.

Volunteer activities: the role of volunteer coordination has been delegated to 87 counties and nonprofit agencies located throughout Minnesota. Recent news coverage documented an extraordinary number of volunteers assisting nonprofits due to the economic recession.

Home and Community Based Services: The DD waiver was established on July 1, 1984. In 2010, more than 14,000 people with developmental disabilities were receiving DD waiver services on a monthly basis at a cost of over \$5,400 per month and total annual expenditures over \$925 million.

Long Term Services/Supports: Federal, state, and local governments spent approximately \$3.9 billion to provide long-term supports to Minnesotans with disabilities and older Minnesotans in 2008. Over 8,000

people with developmental disabilities live in corporate foster care settings (usually 4 person group homes) funded under the DD waiver. Corporate foster care capacity grew 34 percent between 2005 and 2009 with a total of 10,750 corporate foster care beds in 2009. A legislative moratorium was placed on corporate foster care effective July 1, 2009. The number of people with developmental disabilities living in ICF level facilities has decreased since the advent of the waiver. In 1982 there were 7,000 ICF beds and today there are under 2,000 beds.

**(iv) Interagency Initiatives:**

Assistive Technology: In 2007, the GCDD was asked to assist the supervision of STAR, the Minnesota Assistive Technology program. In that same year, STAR and the Council convened a large interagency effort that will bring all hardware, software, and online applications to accessibility standards. Legislation passed in 2009 and standards were adopted. Work continues on this initiative. This technology accessibility effort is led by a variety of individuals with disabilities. The Council also collaborates with STAR on several initiatives such as an AT study, the annual AT Awards Ceremony, AT grants, AT exhibits, AT Advisory Committee meetings, and emergency planning issues for individuals with ASD. The AT Advisory Committee is led by people with disabilities.

Community Services/Individual Support: An ASD project with VRS investigated the feasibility of individuals with ASD being employed in high tech careers. An Employment Forum was held with over 1,600 attendees. People with ASD and family members served as leaders of this initiative.

Document Imaging: The GCDD has worked with a myriad of groups to help promote the independent placements of people with developmental disabilities in document imaging jobs. People with developmental disabilities are the featured leaders.

Governor's Workforce Development Council (GWDC): The GCDD served on a work team that recommended making workforce centers more accessible and the state of Minnesota be a model employer. People with disabilities were active members of this work team.

Quality: The GCDD continues to serve as one of three outside advocates on a legislatively mandated Steering Committee on Outcomes and Performance Measures for all human services. People with disabilities have participated on customer panels.

Justice Issues: The GCDD is working with the Federal Bar Association and others to create CLEs and news releases to bring disability justice

issues to the attention of the justice system. The GCDD has also served as a resource for the Pro Se Project sponsored by the Federal Court system.

Collaboration with Other State Groups: For the past 10 years, the GCDD has been an active member of a collaborative of small disability agencies that meet quarterly. This collaborative planned a year long calendar/campaign to celebrate the 20<sup>th</sup> anniversary of the ADA. The GCDD also organized a media campaign that resulted in television and newspaper coverage of the ADA anniversary. The lead spokespersons were people with disabilities.

In 2007, the small disability agencies launched a one stop website for over 100 state programs and services, products and activities. The GCDD played a lead role in creating this website and updated the site in 2011. Over 2500 unique visitors use the site every month. People with developmental disabilities were asked to test, assess, and provide comments for improvements ([www.mndisability.gov/public/](http://www.mndisability.gov/public/)).

In 2010, the GCDD's online course about lobbying was adapted by the Commission serving Deaf, D/B, Hard of Hearing Minnesotans. Making Your Case is now available in American Sign Language. A person who is deaf led this replication work.

**(v) Quality Assurance:**

Monitoring: There are several agencies involved with the monitoring of abuse, neglect, and exploitation – Minnesota Office of the Attorney General, Medicaid Fraud Unit; Department of Human Services, Surveillance and Utilization Review System (SURS); Department of Human Services, Licensing Division; Ombudsman Office for Mental Health and Developmental Disabilities; and the Department of Health, Office of Health Facility Complaints. The GCDD works closely with each agency.

Legal and Human Rights: The Minnesota Department of Health certifies the ICF/DD facilities in Minnesota. Reports are automatically sent to the Council and the Minnesota Disability Law Center. In Federal Fiscal Year 2010, the most frequent citations were: (1) evacuation drills, (2) the quality of services provided with outside sources, (3) staff treatment of clients, (4) lack of program implementation, and (5) drug administration problems. The number of contacts made to the Ombudsman Office for Mental Health and Developmental Disabilities totaled over 16,772 and the number coming from the area of developmental disabilities totaled almost 3,500 (21 percent).

Of the 1,456 deaths reported, 38% or 553 were deaths of individuals with developmental disabilities. Of the 3,251 serious injuries reported, 58% or 1,886 were individuals with developmental disabilities and 46.2% of these injuries were fractures.

Maltreatment: The total number of maltreatment incidents reported has tended to increase during the past eight years, from 3,976 to 4,649.

Restraint and Seclusion: On July 10, 2009, a lawsuit was filed in Federal District Court, District of Minnesota, on behalf of individuals with developmental disabilities who were restrained with metal handcuffs and leg irons, shackles and other types of restraints; and placed in seclusion at Minnesota Extended Treatment Options (METO). The GCDD has been involved in settlement negotiations, and has reviewed and provided extensive feedback on proposed policies related to key issues.

The Minnesota Disability Law Center (MDLC) issued a report on Restraint and Seclusion of Children in Minnesota Public Schools in February 2010. In 2009, the Minnesota Legislature made significant changes to the laws governing restraint and seclusion in public schools.

Interagency Coordination and Systems Integration: The GCDD served on the initial planning committee that led to the Minnesota System of Interagency Coordinating legislation. The original concept was to extend the interagency coordination of early intervention to all ages. The Individual Interagency Intervention Plan (IIIP) is in place in several counties. The DHS is currently working on several initiatives in the area of quality improvement including: statewide rate setting, standardize provider enrollment, standardize provider standards, increase the number of individuals moving from corporate foster care to owning or controlling their own homes.

Person Centered Planning: In the mid 1980s, the GCDD sponsored several projects to promote person centered planning. During the past 25 years, three publications have been produced and disseminated to over 100,000 people and agencies. It's My Choice continues to be in high demand as a tool to gather individual needs and preferences. The DHS has incorporated person centered planning principles into a comprehensive assessment tool while state operated services has initiated a series of trainings on person centered planning.

Partners in Policymaking: Since 1987, when Partners in Policymaking was created in Minnesota, the GCDD has continuously funded this competency based and values based leadership training program on an annual basis. There are 819 Partners graduates in Minnesota, and more than 17,500 Partners graduates nationally and internationally through

replication of the program. Partners in Policymaking will celebrate its 25<sup>th</sup> Anniversary in May 2012.

Self Determination: The GCDD began the first self determination pilot project in 1986; this is now called consumer directed community supports (CDCS), a service option under several home and community based waivers that give individuals more flexibility and responsibility for directing their own services and supports.

**(vi) Education/Early Intervention:**

General Education: Minnesota has 343 independent public school districts divided into 126 administrative units (intermediate districts, cooperative districts) as well as 87 care and treatment facilities and 154 charter schools.

As of March 2011, a total of 823,826 students were enrolled in Minnesota's 1,992 public schools; of that number, a total of 122,333 students (15 percent) were receiving special education services; and a total of 35,375 students were enrolled in charter schools. For the 2008-2009 school year, a total of 15,653 students were home schooled.

In comparison with other states, Minnesota ranks among the top 10 in several areas including high school diploma (#1), grade 8 math scores (#2), grade 4 basic math scores (#3), grade 4 advanced math scores (#4), best educated index (#6), and bachelor's degree or higher (#10).

Special Education: Minnesota has had a long history of special education of students with disabilities. Some of the earliest programs were permissive until 1957 when special education was mandatory for those children who were "educable" and continued to be permissive for those students with IQs below 50. In 1971, the Legislature passed mandatory special education for all students followed by the Federal law in 1974. Minnesota changed its language from "mental retardation" and mental impairment to developmental cognitive disability in 2000.

The annual Unduplicated Child Count reports the number of students with disabilities under 14 general categories. According to the December 1, 2010 report for Minnesota, the total number of children in special education is 124,298 (preK-12). This includes 8,564 students with developmental cognitive delay, 14,646 students with autism spectrum disorder, 14,505 students with developmental delay, and 431 students with traumatic brain injury. The full report can be found at the Minnesota Department of Education website at

[http://www.education.state.mn.us/MDE/Accountability\\_Programs/Program\\_Finance/Special\\_Education/Child\\_Count/index.html](http://www.education.state.mn.us/MDE/Accountability_Programs/Program_Finance/Special_Education/Child_Count/index.html)

**Early Intervention:** Minnesota has a statewide comprehensive coordinated child find system that ensures that eligible children and youth with disabilities and their families are identified, evaluated and referred for appropriate services under IDEA, Parts B and C and Minnesota Statute 125A.30(b)(2). Child find is a continuous process that depends upon public awareness, screening, and evaluation programs designed to locate children as early as possible.

**Early Childhood:** The mission of Early Childhood Family Education (ECFE) is to strengthen families through the education and support of all parents in providing the best possible environment for the healthy growth and development of their children. Every school district provides ECFE programs.

**Private Schools:** There are over 170 nonpublic schools, both for profit and nonprofit, that are accredited through the Minnesota Nonpublic School Accrediting Association. During the 2009-2010 school year, a total of 77,202 students were enrolled in nonpublic schools, Kindergarten through Grade 12.

Private schools must complete a standard form regarding the IDEA provisions of child find, services, and funding for students with disabilities.

**Educational Support/Performance:** The most recent program performance report was revised by the Minnesota Department of Education on April 15, 2011. Minnesota is meeting the federal targets on several indicators including graduation rates, minimizing drop outs, participation in statewide assessments, reducing suspensions and expulsions, resolution of complaints within 60 days, due process hearing timeliness (45 days), mediation agreements, and state data reported in a timely and accurate manner.

Progress was made (but the target not met) for assessment AYP, proficiency in reading and math, inclusive settings for more than 80 percent of the day, timeliness of parental consent for evaluation, general supervision, and resolution of complaints within 60 days. A total of 2,029 individual student records were reviewed for Part B and 621 records were reviewed for Part C.

**(vii) Housing:**

In 2009, the Legislature called for a study of housing options to explore the availability and affordability of existing housing choices. For individuals using the DD waiver, 55 percent live and receive services in corporate foster care and 45 percent live in their own homes. The average daily cost in corporate foster care is \$197 compared with \$91 for individuals living in their own homes. Between 2005 and 2009, there was a 35 percent increase in the number of corporate foster care homes/services.

The Minnesota Housing Agency (MN Housing) plays a major role in funding the expansion of affordable housing while the federal government has shifted funding to portable vouchers. MN Housing estimates that 520,000 Minnesotans with annual incomes under \$50,000 are cost burdened, paying more than 30% of their income for housing. There are 140,000 affordable housing units in Minnesota but 500,000 households that are cost burdened.

Improvements in affordable accessible housing can be realized by working with other agencies to incorporate universal design features into the state building code (visitability standards have been in place since 2001 for 1,500 rental units and 200 owned units), and continuing to work with communities to enable aging in place through the Communities for a Lifetime initiative sponsored by the Minnesota Board on Aging.

Housing Support/Services: The GCDD worked with the DHS regarding a legislatively mandated housing study that emphasized home ownership and home control. This study is a multi-year, cross disability effort and the Council has provided a presentation as well as meeting separately to provide input and feedback about housing options. Families were involved in several meetings.

The Legislative report contained several recommendations to improve access to rent subsidies, increase accessibility of housing, and keep in place a moratorium on corporate foster care. The report also looked at a shared living model and use of community land trusts as limited equity homeownership models.

The Housing Report recommended improved access to rent subsidies by: continuing the use of vouchers with waivers, coordinating the Money Follows the Person grant so that individuals can leave institutions, improving its work with private sector developers, and promoting HousingLink.

Rent, Own, Modify Residence: Minnesota provides Group Residential Housing supplements for rent payments. Minnesota Supplemental Aid (MSA) provides shelter needy payments for individuals relocating from institutions or living in their own homes under the waiver. Since 1987, MN Housing has funded 500 home improvement or rehabilitation loans to increase accessibility. Minnesota estimates that 1,800 Housing Tax Credit units are accessible. A total of 3,047 HUD units are accessible. MN Habitat for Humanity has built 200 homes that use universal design features.

The GCDD received a state funded grant from DHS to research and identify low cost technology solutions to keep individuals with ASD in their own homes. The emphasis of this grant is on emergency preparedness and emergency responses. People with ASD and families have provided the "voice of the customer" for this effort.

The GCDD also worked with The Arc Minnesota on the Housing Access project that has enabled over 170 people to own "homes of their own" during the past year.

**(viii) Transportation:**

Public Transit: Currently, the Minnesota Department of Transportation (MNDOT) estimates that they are meeting 58 percent of estimated public transit demand because of limited hours and days of service. As of 2009, four counties - Wilkin, Kittson, Pine and Waseca - do not have any county-wide or any city services. Eight counties have services in a city but not county wide services - Clearwater, Cass, Nicollet, LeSueur, Rice, Blue Earth, Freeborn and Olmsted. By 2030, MNDOT estimates the need for \$184 million for greater Minnesota public transit.

Paratransit: The Legislature appropriates about \$24 million in state funds annually to the Metropolitan Council for paratransit services. The federal government provides about \$4.3 million annually and Metro Mobility fares generate another \$3.7 million annually. The Metropolitan Council has policies in place to ensure that Metro Mobility services comply with all state and federal requirements, and staffs and manages the Metro Mobility Service Center.

Metro Mobility service is available 365 days a year. More than 4,300 rides are provided on an average weekday; about 1,000 rides are for people who use wheelchairs. In 2009, a total of 1.45 million rides were provided. Growth is expected to increase by 6% annually over the next decade bringing the total rides provided annually to about 2.3 million in 2020. Service parameters are ADA mandated and include service area,

response time, days and hours of service, advance scheduling limits, capacity constraints, and fares. The ADA service area includes Minneapolis and St. Paul, and nearly 90 adjoining suburbs. Four county ADA transit programs provide service in Anoka, Dakota, Scott, and Washington counties.

Community Access: The MNDOT has a statewide plan for transportation that contains objectives to meet at least 80 percent of transit needs by 2015 and 90 percent of transit needs by 2025.

In 2010, Minnesota spent about \$38 million was spent on medical nonemergency transportation for Medical Assistance recipients. The DHS has oversight of the nonemergency transportation system and, according to the Office of the Legislative Auditor, oversight has been weak. The "special" transportation program has been administered in an ad hoc fashion, without using rulemaking procedures, and without developing formal policies or notifying the public about changes in practices. The Auditor concluded that the 2012 Legislature should reform this transit system by creating a single administrative structure for medical nonemergency transportation.

## **PART C. Analysis of State Issues and Challenges**

### **(i) Criteria for Eligibility for Services:**

The Minnesota Department of Health publishes a 250 page guidebook on eligibility for a wide range of state and federal government programs has been published and is available online at <http://www.health.state.mn.us/divs/fh/mcshn/maze/maze0910.pdf>

Special Services, Waiver Services, Long Term Services/Supports: For DHS health care programs and Medicaid, criteria include U.S. citizenship or certain immigration status, income, assets, disability determination by the Social Security Administration or through the State Medical Review Team.

Medical Assistance for Employed People with Disabilities: Ages 16 to 65 years, employed, has a disability and is not on SSI, asset limits apply, earnings must be more than \$65.00 per month.

Home and Community Based Waiver: For people with developmental disabilities, can be any age, certified as developmentally disabled, needs an ICF/ level of care, must be on Medical Assistance, asset limits apply, residence applies.

TEFRA: Medical assistance eligibility is due to a child's disability but the income of the family exceeds Medical Assistance limits, sliding fee scale applies, must be under age 19, the child must live with a parent, the disability is certified.

MinnesotaCare: Income and asset limits apply, no disability required, sliding fee scale for health care coverage.

Home Care Services (including personal care assistance): The person must be enrolled in Medical Assistance or TEFRA and be assessed for services to assist activities of daily living; prior authorization is needed; services must be ordered by a physician and must be provided in a person's own home.

Family Support Grant: The person must be under age 21 years, certified as disabled, and live in a family home; adjusted income must be \$91,458 or less; can't be on a home and community based waiver at the same time. Expenditures total \$4.1 million in 2008.

Consumer Support Grant: The person must be Medical Assistance eligible and eligible for home care, able to direct own supports, lives in own home, is not on a waiver and needs ongoing supports. Expenditures totaled \$11.9 million in 2008.

Cash, food assistance programs: Eligibility is based on income. For example, Minnesota Supplemental Aid is a small extra month cash payment for adults on SSI.

Food Support (renamed from Food Stamps): Helps people to buy food and eligibility is based on income and size of household.

Group Residential Housing: A monthly payment for room and board if a person has a disability and is over age 18. Expenditures totaled \$90.8 million in 2008.

**NOTE:** Noncitizens can receive assistance as a refugee, asylee, Cuban, Haitian or as an individual fathered by a U.S. citizen during the Vietnam War. These individuals are referred to as "qualified immigrants" and are eligible for SSI, food supports, Medical Assistance, etc.

Early Intervention Services: Minnesota's Help Me Grow program provides services for children birth through age two (Infant/Toddler Intervention) with developmental delays, or a diagnosed physical or mental condition with a high probability of delay resulting; and children three to five years of age (Preschool Special Education) with learning, speech, or play delays.

VRS: Individuals with the most significant disabilities meaning a severe physical/mental impairment resulting in a serious functional limitation in terms of employment in three or more functional areas; and requires multiple services over an extended period of time.

Long Term Services/Supports: The Social Security Administration's PASS Program for SSI recipients allows return to work by setting aside funding to achieve a work goal.

Independent Living Services: Any individual with a significant disability, as defined in 34 CFR 364.4(b), is eligible for Independent Living services under the State Independent Living Services and Center for Independent Living programs authorized under Chapter 1 of Title VII of the Act. The determination of an individual's eligibility for IL services must meet the requirements of 34 CFR 364.51.

(ii) **Analysis of the Barriers to Full Participation of Unserved and Underserved Groups of Individuals with Developmental Disabilities and Their Families:**

Race/Ethnicity/Minority: Minnesota is continuing to become more diverse in race and ethnicity. However, access to services and supports continues to be a problem as evidenced by the percentage of individuals receiving home and community based services or Medicaid funding compared to the proportion of individuals who are Caucasian. The only area of disproportionality is special education where students from minority backgrounds are overidentified.

Disadvantages Related to Poverty: In repeated surveys conducted by the GCDD, individuals who become disabled later in life, live in poverty, and live in rural areas are least likely to have access to the Internet. In addition, poverty plays a critical role in access to health care when co-pays increase. Poverty also plays a part in the development of secondary conditions.

Regarding ESL: A national study is underway to determine the cause of the high prevalence rates of autism within the Somali community,

Rural, Urban: Unemployment is much greater in the most rural parts of Minnesota. Some rural areas have very few services or supports—in other words—there may only be one provider of employment services in some areas of Minnesota.

Attitudes: In surveys undertaken by the GCDD, individuals with developmental disabilities say they are not making key decisions about their own lives because of old attitudes.

Assistive Technology (AT) Users: According to one state study, the most underserved group in receiving AT is African American females in public schools. See AT below for more details about AT users in general.

The GCDD works closely with the State Demographer's Office to determine the most unserved and underserved areas within Minnesota. This cooperation helped us in locating the Family Support 360 Center (Project of National Significance grant).

In addition, the GCDD uses customer and market surveys with the ability to analyze results by age, severity of disability, and geographic location.

**(iii) Availability of Assistive Technology (AT):**

The Assistive Technology Act program in Minnesota, STAR, and its mission is to help all Minnesotans gain access to and acquire the assistive technology they need to live, learn, work and play in the community. STAR is 100 percent federally funded under the AT Act of 1998. Its primary product is the "Directory of Funding Resources for AT in Minnesota."

In 2009, STAR conducted six focus groups around the state of Minnesota. Overall, the focus groups reported positive experiences in terms of device demonstrations, device loans, and device reuse. The most important barriers identified by focus group participants were the lack of awareness of AT options, cost, problems navigating the system, and lack of training and support once a device is purchased.

In 2010, STAR worked with other agencies to create guidelines for the use of monitoring technology in corporate foster care homes.

As noted in the housing section, visitability standards are in place but the Department of Human Services recommends that universal design principles be incorporated in the State Building Code. Universal design has been a guiding principle for Vocational Rehabilitation Services and Workforce Centers.

According to the Institute on Community Inclusion (ICI), University of Massachusetts, Boston, rehabilitation technology was provided by the VRS in placing individuals in competitive employment. A total of 9% of individuals who received rehab technology were not competitively employed at the time of closure of the case; while seven percent were

competitively employed. Of the total of 166 individuals who received rehabilitation technology, 133 were employed without supports in an integrated setting, 11 were self employed, four were in a state agency-managed BEP, five were homemakers, and 13 were employed with supports in an integrated setting.

According to a national study conducted by the Pew Internet Project, two percent of American adults say they have a disability or illness that makes it harder or impossible for them to use the Internet. Other national findings indicate that disability is associated with being older, less educated, and living in a lower-income household. Those living with a disability report lower rates of Internet access than other adults. In rural areas, the problem is compounded by a lack of access to broadband connections.

In 2009, the GCDD conducted a study to determine access to and use of information technologies among Minnesota households that include people with developmental disabilities compared to the general state population. A total of 382 surveys were completed; 22% of the respondents were households with a family member with a disability.

Findings showed that two-thirds of the households surveyed have broadband Internet access. Households with people with developmental disabilities appeared to have equal access to computers and the Internet compared to the general population; however, they use information technology differently. They are more frequent daily users; more likely to access government websites; and use information technology more for entertainment, community information/involvement, voice and video IP communications, online courses, and lobbying/communicating with elected officials.

The 2007 Minnesota Legislature directed a statewide study on AT. Results showed that AT is an investment that enables Minnesotans with disabilities to be part of their communities, ongoing coordination is needed among all parties concerned with AT, and AT can increase/improve citizen participation into the future. There is no uniform data collection method that captures all public funding for AT.

The DHS is the largest state agency that funds at with more than \$7.1 million spent on durable medical equipment and supplies/modifications excluding funding spent by managed care organizations. The Deaf and Hard of Hearing Services Division assists individuals who are deaf/hard of hearing through information and referral (7,035 people) and a telephone equipment distribution program (1,100 items for 4,200 people).

STAR reached over 44,000 people over three years through personal contacts, events, and their website. The top concern is funding for AT.

**(iv) Waiting Lists:**

In 2009, the total number of persons in need of and waiting for residential services in the next year, per 100,000 was 2,853. The total number of persons waiting for other services per 100,000 was 598.

Description of the State's Wait List Definition: Minnesota statutes set the parameters for waiting lists for the four waiver programs. For the DD waiver, counties are required to maintain a waiting list of persons with developmental disabilities specifying the services needed but not provided. The waiting list must be used by counties to assist them in developing needed services or amending their children and community service agreements.

Counties periodically reevaluate the needs, choices, and options for individuals waiting for waiver services; and prioritize the allocation of waiver resources – Children with service needs to avoid out-of-home placement; individuals affected by private sector ICF/DD closures, individuals with immediate risk of out-of-home placement; individuals with immediate risk of ICD/DD placement. Counties meet with individuals to review continuing need for/interest in DD waiver services and update screening information in MMIS at least every three years (Minn Stat Section 256B.092).

How Individuals Are Selected for the Waiting List: Minnesota selects individuals to be on the waiting list based on need data that is captured on the DD Screening document, by age, and current living arrangement.

The DHS establishes statewide priorities for individuals needing CAC, CADI, or TBI waivers according to specific criteria - unstable living situations due to the age, incapacity, or sudden loss of the primary caregivers; moving from an institution due to bed closures; sudden closure of their current living arrangement; require protection from confirmed abuse, neglect, or exploitation; sudden change in need that can no longer be met through state plan services or other funding resources alone; other DHS priorities. When allocating resources to counties, consideration must be given to the number of individuals waiting who meet statewide priorities, and the county's current use of waiver funds and existing service options (Minn. Stat. § 256B.49).

Services Individuals On the Waiting List Are Receiving: Individuals on the waiting list may be receiving no services, only case management services,

inadequate services, or comprehensive services but waiting for preferred options.

As of October 30, 2009, a total of 3,858 individuals were on the DD waiver waiting list. Of that number, 3,166 were birth to age 22; a total of 670 individuals were ages 23 to 64; and 21 individuals were over age 65. Approximately 90 percent of all individuals on the DD waiting list are living in the homes of their immediate or extended families. For individuals on the waiting list, the most frequent services currently received are case management, special education, and PCA.

In 2010, a total of 3,552 individuals were waiting for DD waiver services (compared with 3,858 in 2009). Of this total, 3,136 individuals were receiving some type of service(s) while 416 individuals were without any services. Of those individuals who were receiving some type of long term care or home care services, the greatest number (1,983) were receiving personal care services. A total of 2,560 individuals had access to "basic care" services including dental care, and pharmacy and physician services. A total of 388 individuals were receiving targeted case management services.

During the 2011 Legislative session, little progress was made in dealing with waiting list issues. The economic recession and state budget deficit prevented any expansion of waivers.

Individuals on the waiting list have gone through an eligibility and needs assessment. During the screening process, the county case manager discusses how soon DD waiver services are needed based on the needs of the person and his/her support system. Of the 3,858 individuals on the waiting list for the DD waiver, 2,967 are in need of services in 12 months or less (77 percent); 506 are in need of services in 13 to 36 months (13 percent); and 385 are in need of services in 37 months or later (10 percent).

There are structured activities for individuals/families waiting for services to help them understand their options or assistance in planning their use of supports when they become available.

Other Data/Information Related to Wait Lists: A Long term Care Consultation Screening Document is used to screen individuals who are interested in CAC, CADI, or TBI waiver services. Counties may have waiting lists for these waivers due to limits on waiver growth or needing to develop resources to meet an individual's needs. As of November 2009, a total of 598 individuals had been screened for one of these waivers.

A total of 2,096 individuals were in nursing facilities and could be eligible for the CADI waiver.

(v) **Analysis of the Adequacy of Current Resources and Projected Availability of Future Resources to Fund Services:**

Employment Funding/VRS: In 2008, expenditures for Extended Employment totaled \$14.9 million, expenditures for VRS totaled \$49 million, and expenditures for Independent Living services totaled \$5.6 million.

The VRS provided estimates for the number of people to be served and the costs of those services in their most recent state plan that was updated in September 2010.

In FFY 2011, VRS estimates serving about 21,500 people under Title I of the Rehab Act; all of whom will have a significant disability. It is estimated that 14,400 will have the most significant disabilities and that 7,100 will be people with a significant disability.

It is estimated that 150,000 people are eligible for vocational rehabilitation services but, under the order of selection, 14,400 people have three or more serious limitations (most significant disabilities). In order to serve those with the most significant disabilities, \$34.5 million is needed; for those with two or more serious limitations, 5,900 persons will have a total program cost of \$13.7 million; for the 1,200 people with one significant limitation, approximately \$2.8 million is needed.

A separate estimate for supported employment was submitted to the U.S. Department of Education. If 2,200 individuals are served, then a budget of \$5.4 million is needed for total program costs; of that amount, \$2.6 million is for purchased services.

A total of \$18.5 million in Title I and Title VI funds are needed in order to serve 21,500 people at an average cost of \$860.

Transit Funding: \$38 million for nonemergency transportation; \$24 million for Metro Mobility (ADA paratransit services) with \$3.7 million additional funds generated in fares.

More than \$2.1 billion in ARRA funds was received by DHS programs; the majority of funds was used to increase federal matching funds for the state Medicaid program. The increase of federal funds resulted in a match rate change from 50 percent federal to 61.59 percent federal over a 33 month period. A total of \$110 million was received for health care, state operated services, and the Minnesota sex offender program.

Special Education: Costs have risen steadily from FY 1999 (\$937 million) to FY2007 (\$1.5 billion) to FY 2010 (\$1.725 billion), and are projected to increase up to \$2.155 billion by FY 2015. The revenues have increased at

a slower rate and as a result, there is a special education cross-subsidy provided from general education revenues. Due to federal stimulus funds (ARRA) the cross subsidy dropped to \$491 million but will rise to \$518 million in FY 2011 and will reach \$742 million in FY 2015.

Waivers: In 2010, additional case load limits were imposed for the DD, CADI, and TBI waivers. Reductions in CADI waiver funding will result in 720 individuals per year. Reductions in TBI waiver funding will result in 72 individuals per year. Reductions in DD waiver funding will result in 72 individuals per year. This is a \$27 million reduction in state and federal funds over three years. If all of the individuals currently on the DD waiver were served, a rough estimate would be \$70,000 per person x 4,000= \$280,000,000.

Independent Living Services: There are 11 unserved counties (13%), meaning that no core services are available to residents. Community needs are seldom addressed, there is no designated contact or referral and no detailed information gathered about needs.

There are 47 underserved counties (54%), meaning limited access to and availability of core services. Community needs are occasionally addressed, there are limited contacts with information and referral, and only anecdotal information collected about needs.

If funding becomes available, priorities are to maintain funding levels, provide a cost of living allowance, fund Centers that are under minimum funding levels, and then begin expansion. No cost estimates were provided.

**(vi) Adequacy of Health Care and Other Services/Supports/Assistance:**

The Patient Protection and Affordable Act contained general provisions that apply to children with special health care needs including the prohibition of health coverage rescissions, prohibition of lifetime limits on essential benefits, the extension of dependent coverage up to age 26 years, and prohibition on preexisting conditions.

Minnesota Maternal and Child Health Studies: The most important service gaps identified by public health departments include mental health providers, dental providers, chemical health providers, specialty areas, primary care providers, and family planning services.

Caregiver burden is high among CYSHCN families especially if the child has a mental or emotional disability; 40 percent of families reported additional stress.

There is a severe shortage of mental health services in rural areas with greater stigma for families seeking assistance. More than half of the families indicated that they are receiving medical home coordinated care. Over 90 percent of the families said that the community based service system is organized to use service easily.

There are six core outcomes for CYSHCN and Minnesota scores higher than other states for use of medical homes, insurance rate participation, individuals receiving services, absentee rate (lower than other states), specific conditions do not hinder activity levels, connection to a personal doctor or nurse, participation in family centered care, and amount of time needed to coordinate health care (lower than most states).

In 2009, DHS conducted a Managed Care Public Programs Consumer Satisfaction Survey. Individuals who were current enrollees and had been enrolled for five of the last six months of 2008 were surveyed. Two programs include individuals with disabilities –

Minnesota Disability Health Options (MDHO), a managed care program for people with physical disabilities ages 18-64;  
Special Needs Basic Care (SNBC), a managed care program for people with disabilities who are Medical Assistance eligible and ages 18-64.

Survey questions/results were combined into eight topic areas; the most positive answers being a **9-10** rating for all health care, personal doctor, specialist seen most often, and health plan overall; and **always** for getting needed care, getting care quickly, how well doctors communicate, and customer service.

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For MDHO, the first four items received a **9-10** rating by an average of 57.5% of enrollees (range of 48% - 64%); the last four items were rated **always** by an average of 57% of enrollees (range of 50% - 72%).

For SNBC, first four items received a **9-10** rating by an average of 60% of enrollees (range of 50% - 70%); the last four items were rated **always** by an average of 63% of enrollees (range of 54% - 74%).

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Overall, counties in the southeastern part of the state, where Mayo is located, ranked highest (between 1 and 21 out of 85), and counties in the northern half of the state ranked lower (between 43 and 64). Two of the Twin Cities metro counties, Hennepin and Ramsey, also ranked lower – 48 and 59 respectively.

Health Care Service Reductions: Seven health care plans issued a report calling for massive cuts in services especially targeted at people with disabilities. The recommendations included: (1) targeted reductions to the waivers, (2) reductions in PCA services, (3) move individuals with disabilities to managed care, and (4) expand alternatives to personal care assistance services. This report was met with opposition from the disability community because of the poor factual basis of the conclusions.

In 2004, the GCDD conducted a Minnesota Health Care Opinion Poll Study to gather opinions from Minnesotans about their current feelings on key health care issues; 800 individuals were interviewed. Ninety-five percent of respondents reported having some kind of health insurance coverage; four out of five of those with coverage had private insurance, either exclusively or in combination with public insurance. Among households with a person with a disability, more than 1 in 4 had delayed medical treatment because of costs and, in almost three quarters of these cases, the condition was serious.

**(vii) Adequacy of Home and Community Based Waiver Services:**

Thomson Reuters discussed several systems issues in their report, *Minnesota State Profile Tool*.

Complexity of the system and the need for greater coordination and collaboration: No single organization serves all disabilities based upon functional needs rather than diagnosis. Multiple agencies serve children with disabilities and many organizations provide services to people with developmental disabilities. Adding to the complexity are the 87 counties that deliver services, provide eligibility assessments, serves as case managers, offer Long Term Care Consultations and perform other functions such as administration, provider enrollment, and contracting. Managed care organizations intersect for older adults and people with disabilities and/or mental illness. Minnesota also has over 300 school districts, regional area agencies on aging, local public housing authorities, and thousands of providers and nonprofit organizations.

Information and Referral: There are multiple methods of receiving information and referral including: county agencies, managed care organizations, local school districts, case managers, vocational rehabilitation, area agencies on aging, providers, and word of mouth especially families to families. There are multiple online and telephone resources, specific advocacy organizations, and human resource offices at places of employment. In addition to MinnesotaHelp.Info, several disability groups organized a one stop website for disability issues called MNDisability.Gov.

Housing Options: An insufficient supply of housing options can lead to homelessness and unnecessary institutional placement. In 2006, 79 percent of adult homeless Minnesotans had a disability and 60 percent had multiple disabilities. The most common disabilities were serious mental illness, chronic physical health conditions, cognitive disabilities, head injuries, and substance abuse. Homeless individuals use crisis services more frequently than other groups. Another frequent challenge is the lack of affordable, accessible housing for people leaving nursing homes. Most individuals with developmental disabilities who receive home and community based services live in four person corporate foster care settings. The Legislature imposed a moratorium on adult foster care development in 2009.

Infrastructure Development: Multiple issues are facing Minnesota including the recruitment and retention of staff, limitations in funding, the looming impact of the aging population, and changes that could occur during this legislative session. The DHS has received a Medicaid Infrastructure Grant since 2001. The MA-EPD program allows people with disabilities to earn income and pay a premium to maintain Medicaid benefits.

Self Directed Services/Supports: Minnesota offers flexibility in self directed services and supports; people with developmental disabilities are the leading group in terms of numbers of people (1,404) using this option. However, in 2007, the Office of the Legislative Auditor pointed out wide discrepancies in the use of this option especially in rural counties. As a result, administrative requirements have increased and the number of participants have declined. Minnesota also allows payment of waiver funds to spouses and parents of minor children as caregivers. Payment to legally responsible relatives is not allowed for state plan services. A few of these issues are under reconsideration during the 2011 Legislative Session.

In May 2010, DHS created a new website section that enables users to examine the adequacy of waiver services by location (counties) and allows examination of housing types, services provided, earned income and proportionality of community funding.

The national UCPA published a state by state comparison regarding inclusion. Minnesota ranks 13<sup>th</sup> in allocating resources to those in the community with 90 percent spent on community services; ranks 45<sup>th</sup> in supporting individuals in the community in settings under 4 people with 66 percent living in settings with 1-3 settings; ranks 20<sup>th</sup> in keeping families together through family support programs with 157 families supported per 100,000; and ranks 35<sup>th</sup> in supporting meaningful work.

## **PART D. Rationale for Goal Selection**

Surveys of individuals with developmental disabilities and their families were done in 2000, 2005, and 2010 to develop the Five Year State Plans. Overall, IPSII levels have increased and there is greater agreement about some key aspects of IPSII, although inclusion continues to be the most difficult for people with developmental disabilities to achieve. The exception is with the young adult age group (14 to 18 years) who are the least satisfied with all of their IPSII levels, integration and inclusion being the most elusive. Unemployment and underemployment rates among people with developmental disabilities remain stagnant and high even though the majority want to work, and those who are employed want more hours and feel they are not as productive as they could be.

The 2000 Quality of Life Assessment Survey asked individuals with developmental disabilities about their satisfaction levels with independence, productivity, and integration and inclusion (IPII). Self determination was added later. Personal interviews were done to get a better understanding of individual situations and the meaning of IPII in everyday life. Respondents were far more satisfied with their level of independence (64 per cent) than inclusion (55 per cent) and, overall, young adults with disabilities were more likely to be dissatisfied than adults with these attributes. Satisfaction with productivity levels was strongly related to severity of disability; 22 per cent were clearly not satisfied and some felt their potential to be productive was untapped.

Nearly 25% of respondents were dissatisfied with their current level of integration, considered a step toward inclusion. Being treated as an equal (a person without a developmental disability) and having the resources and support available to create and nurture relationships were seen as drivers of overall satisfaction with integration. Inclusion was rated the lowest; the opportunity to develop personal relationships and friendships with others, and being treated with respect and as an equal were key aspects of this attribute.

The 2005 Individual Survey was based on the 2000 survey which served as a benchmark; self determination was added. Less than half the respondents said they had enough money to live on, knew what to do if their health or safety was in jeopardy, or felt their future would be secure. Individual respondents were more likely to agree that their basic needs were being met than parents, friends or others who assisted them in completing the survey.

A total of 60 percent were satisfied with their current level of independence; 53 percent were satisfied with their current level of productivity. Individuals' feelings of productivity; 61 percent were satisfied with their current level of self determination; 59 percent were satisfied with their current level of integration; and 54 percent were satisfied with their current level of inclusion.

The 2010 survey showed that the young adult years, ages 14 to 18, continue to be particularly challenging for people with developmental disabilities. They are most likely to indicate that their disability severely impacts their capabilities and most likely to believe their basic needs are not being met.

A Public Opinion Poll, originally conducted in 1962 to measure awareness and attitudes about people with developmental disabilities, was repeated in 2007. The results showed that Minnesotans overwhelmingly agreed that society should do everything possible to help those individuals who are most vulnerable and supported a broad range of government services -

The best way to care for people with developmental disabilities is through their immediate family, as much as possible.

Over 90% believed that, with the right training, people with developmental disabilities could be very productive workers.

85% of respondents strongly agreed that they have a lot of respect for companies that employ people with developmental disabilities.

From data collected, gaps and needs were identified. Proposed goals were aligned with other national goals based on past experience and results. GCDD members reviewed and commented on the goals, and made additions and revisions. The proposed goals were posted on the GCDD website for public review and comment. Substantive comments were incorporated into the final goal statements and approved by the GCDD on April 6, 2011.

## **PART E. Collaboration**

### **(i) As a Network:**

Voting Rights: The MDLC is the lead agency on voting rights. The UCEDD (Institute on Community Integration) and GCDD are strong supporters of voter registration efforts. The MDLC led the efforts to block a restriction on voter rights for anyone under guardianship during the 2011 Legislative session. A GCDD member (self advocate) served as a witness and also serves on the Secretary of State's advisory committee on voting rights.

Employment: The DD network participated in an Employment Forum featuring Temple Grandin. Over 1600 people attended and three major Minnesota companies (3M, Cargill, and Best Buy) served as co-sponsors; the Autism Society of Minnesota was lead agency.

The GCDD is working with DD network partners on a potential federal lawsuit about day programs, integrated employment, and wages.

Positive Behavior Support: The DD network has begun work on a resource center for positive behavioral supports and interventions to be housed at the UCEDD at the University of Minnesota. The MDLC and GCDD will participate in the development of the center and serve on an advisory committee.

The federal settlement agreement calls for an Olmstead Committee and a Rule 40 committee to rewrite the aversive/deprivation rule in Minnesota. These activities will involve the MDLC, ICI, and the Council.

Public Television: In cooperation with Lutheran Social Service of Minnesota, public television, and the DD network, a documentary, *Institutions to Independence*, was produced and disseminated. Self advocates are featured and were also interviewed about rights for an essay, *Know Your Rights*.

Seclusion and Restraint: Minnesota is engaged in public discussions regarding the use of seclusion and restraints for children and adults in local school districts and state-operated programs. A primary concern and focus are persons who present significant challenging behaviors in their communities. The DD network will work to eliminate the use of prone and other restraints, and seclusion of children and adults with developmental disabilities.

Self Advocacy: In response to a need for a united self advocacy group, Self-Advocates Minnesota (SAM) was started. The DD network works with SAM and its members to support this effort. In 2010, a total of 1,211 self advocates attended 63 training sessions, and 43 self advocates were trainers.

**(ii) With Each Other:**

With UCEDD:

Abuse: The GCDD worked with the UCEDD LEND program on a paper regarding abuse and neglect issues affecting people with autism spectrum disorder and other developmental disabilities. The Council also worked with William Mitchell College of Law regarding a paper about victims with developmental disabilities and competency to testify.

Public Television: In 2011 and 2012, public television is undertaking a new initiative, *Honoring Choices Minnesota*, dealing with end of life conversations. The UCEDD and GCDD served as interviewees for the project. Individuals and family members were videotaped regarding how to

handle/model end of life conversations at the June 1, 2011. The online video clips and tools will be hosted at public television with links to the DD network in 2012.

With P&A:

Legal Assistance: The GCDD has established a partnership with the Minnesota Chapter of the Federal Bar Association (FBA) and prominent attorneys to conduct CLEs on disability and social justice issues that meet Ethics and Diversity CLE requirements.

The GCDD has also established a partnership with the Minnesota *Pro Se* Project, a joint effort of the FBA and the Federal Court system, to enable greater access to the justice system by a wide range of poor people including minority groups, people with disabilities, and women of color. The *Pro Se* Project offers free CLE credits to attorneys who offer their services. The four Minnesota law schools also cooperate and law school students, under the supervision of an attorney, are able to work with litigants.

The American Bar Association recently selected the Minnesota Chapter of the FBA to receive the 2011 Harrison Tweed Award, one of the ABA's most prestigious honors and the highest award in the legal services category.

The GCDD and MDLC will continue to work with bar associations, the judiciary, and other organizations to increase the availability of pro bono legal services for individuals with developmental disabilities.

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(iii) **With Other Entities:**

Abuse: A work group was created to discuss concerns about the involuntary use of Electroconvulsive Therapy (ECT) and proposed legislative changes that would include individuals with developmental disabilities but left open questions of adequate safeguards and protections for them. The GCDD participated in this work group.

Employment: The Council is working with the DD network partners on a potential federal lawsuit regarding day programs, integrated employment, and wages. The focus of this effort will be to reduce the segregated employment of individuals with developmental disabilities and segregated employment practices.

Systems Change: The DD network worked with other disability groups to defeat a state legislative proposal to eliminate OT, PT, speech, and

audiology services in the Minnesota's Medicaid programs; and also worked to secure funding and develop legislation for alternative services for individuals with developmental disabilities who would lose eligibility for PCA services in 2011.

Emergency Planning/Preparedness: A Project of National Significance (PNS) grant was awarded to IPSII, Inc., a nonprofit organization created by a Minnesota Partners graduate, to design and develop a Family Support Center on Emergency Preparedness in the Jordan neighborhood of North Minneapolis. The DD network served as advisors and faculty for the project.

The GCDD received a grant from DHS to investigate the use of low cost technology that would make it possible for individuals with autism spectrum disorder (ASD) to remain in their own homes, and be prepared for and manage a variety of emergency situations. Individuals with ASD and family members, and first responders want to build stronger relationships, are receptive to learning from each other, and welcome education and training to increase awareness and understanding around this topic.

ADA: The GCDD organized a workshop, "The ADA: Have We Made Any Progress," to help celebrate the 30<sup>th</sup> Anniversary of the ADA. Faculty included the United States District Court, District of Minnesota; Minneapolis Area Office of the EEOC; and United States Attorney's Office for the District of Minnesota. The MDLC and ICI assisted with planning efforts and facilitated round table discussions.

## **SECTION IV. FIVE YEAR GOALS**

**GOAL #1 Employment:** Increase opportunities and the supports needed by individuals with developmental disabilities to be employed in integrated settings at or above minimum wage and benefits by:

- A. Educating and building the capacity employers, and creating employer incentives that contribute to workforce development;
- B. Providing increased supports that may include technology and are necessary for a broad range of employment options including competitive, customized, or self employment;
- C. Increasing access to inclusive postsecondary education and other career focused training opportunities; and
- D. .Increasing the expectations of individuals and families about the importance of work opportunities during high school (transition years) and adult years, by utilizing their personal networks to reach public and private sector employers, and identify job experiences in the community.

### **Objectives:**

1. At least 10 individuals with developmental disabilities will be employed in a broad range of inclusive employment settings each year.
2. The particular type of job, hours worked, hourly wages and benefits will be tracked.
3. Two employers will directly employ individuals with developmental disabilities.
4. Two businesses will receive training on disability relate employment issues.
5. Two schools will be preparing students in transition for postsecondary education and jobs/careers of their choosing.

**GOAL #2 Partners in Policymaking:** Support and promote the development of leadership skills for families of children with developmental disabilities and adults with disabilities as advocates, spokespersons, and members of the larger disability rights movement by educating people about rights, self determination, engagement in public policy advocacy and learning best practices in the areas of education, technology, housing, employment and other aspects of community participation. Provide face to face training, online learning, blended learning, and graduate workshops as a means of reaching people and strengthening personal leadership skills.

**Objectives:**

1. Educate adults with disabilities and parents of young children with developmental disabilities about rights, self determination, public policy advocacy, best practices in education, technology, housing, employment and other aspects of community participation.
2. Thirty-five individuals will complete 128 hours of leadership training and graduate from the classroom Partners program each year; and 90% will report customer satisfaction and improvement in IPSII.
3. Provide face to face training, online learning, and blended learning. At least 50% of Partners participants will review one of more online courses and complete the Feedback Form.
4. Provide graduate workshops as a means of reaching people and strengthening personal leadership skills. A total of 200 Partners graduates will participate in a graduate workshop in Year 1 (Partners 25<sup>th</sup> Anniversary), 40 Partners graduates will participate in a graduate workshop in Years 2-5; and 90% will report customer satisfaction and improvement in IPSII.
5. Provide a networking opportunity to increase awareness and engagement in public advocacy; 400 Partners graduates/Partners coordinators will subscribe to the Partners listserv each year and 90% of quarterly survey respondents will report customer satisfaction and a positive learning experience.
6. Conduct longitudinal studies to determine the long term effectiveness of the Partners program; 40% of Partners graduates will participate in the longitudinal study; 85% of Partners graduates surveyed will show improvement in IPSII and 90% will report good to excellent leadership skills.

**GOAL #3 Cultural Outreach:** Support the development of leadership skills in culturally diverse communities through collaborative efforts with organizations in these communities to increase awareness and knowledge, and develop skills that will encourage participation in the Partners in Policymaking program and joining with the larger disability rights movement.

**Objectives:**

1. Provide outreach and introductory leadership skills training that reflects the concepts and values of the Partners program.
2. Forty-five individuals will complete 30 hours of introductory leadership skills training each year, a step to participating in the Partners program; and 90% will report customer satisfaction and improvement in IPSII (baseline, mid-year, end of year surveys).
3. Five graduates will be referred to the Partners program.

**GOAL #4 Self Advocacy:** Develop a statewide network of well trained and informed self advocates by fulfilling the federal DD Act requirements –

- A. Establish or strengthen a program for the direct funding of a state self advocacy organization, led by individuals with developmental disabilities;
- B. Support opportunities for individuals with developmental disabilities who are considered leaders to provide leadership training to individuals with developmental disabilities who may become leaders;
- C. Support and expand participation of individuals with developmental disabilities in cross disability and culturally diverse leadership coalitions (Public Law 106-402, Section 124(b)(4)(ii);

And assist in identifying alternative/other funding opportunities.

**Objectives:**

1. Establish or strengthen a program for the direct funding of a state self advocacy organization, led by individuals with developmental disabilities and assist with identifying alternative funding opportunities.
2. Fifty self advocates will participate in training sessions each year, and 90% will report customer satisfaction and improvement in IPSII.
3. Support 10 individuals with developmental disabilities to provide leadership training.
4. Support/expand the participation of five individuals with developmental disabilities to serve on cross disability/culturally diverse coalitions.

**GOAL #5 Training Conferences:** Provide ongoing education and training that reflect and incorporate the values in the DD Act in programs and supports for people with developmental disabilities that will lead to greater networking and partnering with others across the state through a variety of delivery modes including face to face, online learning, postsecondary educational opportunities, and blended learning.

**Objectives:**

1. Deliver 10 training conferences/workshops through a variety of opportunities including face to face learning, postsecondary education opportunities, blended learning, etc. to 1,000 individuals each year.
2. At least 90% of attendees report customer satisfaction and an overall quality rating of the conference/workshop.

**GOAL #6 Publications, Websites, Online E-Learning Courses:** Provide information, education, and training that increases knowledge, skills and abilities of end users through a broad range of multiple media formats by:

- A. Promoting accurate historical archiving of resource materials;
- B. Investigating and using the latest technological advancements in communications that may include social networking;
- C. Showcasing the positive roles and contributions of people with developmental disabilities; and
- D. Increased marketing efforts to ensure wide dissemination of Council products.

**Objectives:**

- 1. Promote accurate historical archiving of resource materials;
- 2. Investigate/use the latest technological advancements in communications that that may include social networking and development of apps for advocacy.
- 3. Increase marketing to ensure wide dissemination of GCDD products.
- 4. 90% of visitors report customer satisfaction and improvement in IPSII.

**GOAL #7 Customer and Market Research:** Conduct or commission research studies to measure and assess quality outcomes of the federal DD Act through annual qualitative and quantitative surveys on new topics/issues or further research on topics/issues previously studied.

**Objectives:**

1. Conduct a qualitative survey regarding definitions of IPSII in Year 1; a total of 50 individuals will be surveyed; participation rate will be 75%.
2. Conduct a 50 Year Opinion Poll 1962-2012 in Year 2; a total of 600 Minnesotans will be surveyed; participation rate will be 30%.
3. Conduct a research study on education issues in Year 3; a total of 150 individuals will be surveyed; participation rate will be 20%.
4. Conduct a possible research study on employment and test the market for effective measures regarding the benefits of a diverse workforce in Year 4
5. Conduct individual and provider surveys in Year 5 to collect input for the FFY 2017-2021 Five Year State Plan; a total of 200 individuals will be surveyed; participation rate will be 30%.

**GOAL #8 Quality Improvement:** Identify and implement an approach that promotes continuous quality improvement and apply to all Council work.

**Objectives:**

1. Apply a comprehensive quality improvement approach to the GCDD's Annual Work Plan, Annual Report, monthly reports, and ADD Program Performance Report.
2. A total of 100 hours of training will be provided.
3. A 10% ROI improvement ratio will be realized each year.

## **SECTION V. EVALUATION PLAN**

### **PART A. How the GCDD Will Examine Progress in Achieving Goals**

Since 1997, the Council has utilized and applied the National Baldrige Criteria for Performance Excellence, the best of business standards. The Baldrige framework of excellence contains 11 core values and seven concepts that reflect the customer focused and results oriented Baldrige Framework. The Council's Annual Work Plan and monthly reports are based on the Framework.

Quarterly Operations Reports are prepared and submitted internally to the Commissioner of the Department of Administration, and followup in person review meetings are scheduled. Prompt payment of invoices is monitored and reported on a monthly basis by the Department of Administration, Financial Management and Reporting division.

Council website surveys welcome compliments and complaints; these are reviewed for actionable items. Data is collected monthly; complaints are responded to immediately and technical issues are referred to the Council's webmaster for trouble shooting and/or resolution

State Services for the Blind has a compliments and complaints line and feedback can be submitted at their website for any problems with accessibility of technology (hardware, software, online applications, websites).

Performance goals are written into supplier contracts and performance is grounded in the principles of customer focus, stakeholder value, and process management. Partnerships are established and strengthened with suppliers, and the concepts of quality and continuous improvement guide grant projects and activities to improve customer results. Suppliers are also required to collect data for the ADD Customer Satisfaction Survey form. The Council's Grant Review Committee conducts face to face mid-year performance reviews with all key suppliers; reviews are framed around contract performance goals, achievements and accomplishments to date, and ideas and suggestions for process improvements that can lead to increased customer outcomes and IPSII results.

### **PART B. Methodology to Determine If Needs Identified Are Met and Results Achieved**

Data are collected on an ongoing basis, and summarized and reported annually in a Business Results report (charts, graphs, and trend lines for key business measures including IPSII results) and an Annual Report (highlights of grant projects/activities and supplier performance results based on the Program Performance Report). Both reports are posted on the Council website.

Customer satisfaction data is collected by all suppliers on an ongoing basis and *stakeholder satisfaction data are collected annually; results are included in the annual Program Performance Report.*

IPSII data are collected on Feedback Forms that are included in each of six e-learning courses, the online version of the Partners in Policymaking classroom leadership training program; the Partners program itself; cultural outreach programs in the African American and Latino communities; and self advocacy.

Customer market surveys also provide a means of identifying needs and measuring the results achieved.

The Council's quality consultant did an onsite examination on grant recipient records, data collection processes, and integrity of data systems during the past year. A report was provided to the full Council.

Every grant recipient is expected to use the ADD Customer Satisfaction Survey, and the Council's IPSII pre and post evaluation forms; collect qualitative results from customized evaluation forms; and prepare and submit narrative progress on a quarterly basis as outlined in performance contracts. All grant recipient results are then reported in monthly activity reports and rolled up to the annual Business Results, the Council's Annual Report, and the ADD Program Performance Report.

The quality consultant also assists the Council by calculating ROI measures.

### **PART C. Council's role in reviewing and commenting on progress towards reaching the Plan goals.**

The Council's Annual Work Plan is aligned to the Baldrige Criteria, and includes the annual goals and objectives contained in the Five Year state Plan. The Council reviews and approves the Work Plan at the October meeting.

The Council receives, reviews, and comments on the monthly activity reports that contain progress data on goals and objectives, evaluation data, and IPSII results. The Executive Director's Reports also allow time to discuss progress.

The GRC conducts face to face mid-year supplier performance reviews with all key suppliers on an annual basis. Reviews are framed around contract performance goals; and key grant recipients present updates on accomplishments to date, results achieved, and ideas and suggestions for process improvements that can lead to increased customer outcomes and IPSII results. These reviews are summarized and presented to the full Council.

During the preliminary allocation process for grant programs/projects in June and the final allocation process in August, all performance results are summarized for the full Council so that review and comment can be shared.

At the December Council meeting, the Baldrige Results are presented, and review and comment are solicited. These results are posted on the Council website along with the Annual Report.

**PART D. How the annual review will identify emerging trends and needs as a means for updating the Comprehensive Review and Analysis.**

In following the Baldrige Criteria, the Council undertakes ongoing environmental scanning which includes daily reviews of national listservs for news and updates (i.e. every Council member receives *Inclusion Daily Express*). As noted earlier, Council staff reviewed hundreds of Legislative reports, websites, and needs assessments to prepare the State Plan Comprehensive Review and Analysis. This process includes regular reviews of key state agency websites, regular reviews of the Legislative Reference Library acquisitions, and reviews of national PNS data collection websites.

The Council also sponsors an external customer/market survey that enables in-depth study of a specific trend or need, such as employment issues. The survey results are always presented to the full Council and posted on the Council website.

Through grants received from other state agencies, the Council has been able to investigate emerging needs and trends regarding Autism Spectrum Disorder.

Another method of monitoring trends and needs comes from the careful historical archiving work for the Council's websites. The Council imports important documents and resources about emerging trends and needs through a regular updating process, and also hosts national subject matter experts as presenters who can speak to related issues.

Through a combination of methods and approaches, the Council is able to update the Comprehensive Review and Analysis.

## SECTION VI. PROJECTED BUDGET

<b>Goal</b>	<b>Subtitle B \$</b>	<b>Other \$</b>	<b>Total</b>
Employment	\$ 75,000	\$ 3,500	\$ 78,500
Partners in Policymaking	\$ 210,000	\$ 84,603	\$ 294,603
Cultural Outreach	\$ 85,000	\$ 27,300	\$ 112,300
Self Advocacy	\$ 100,000	\$ 34,000	\$ 134,000
Training Conferences	\$ 20,000	\$ 118,275	\$ 138,275
Publications, Websites Online E-Learning Courses	\$ 166,503	\$ 1,725	\$ 168,228
Customer/Market Research	\$ 50,000	\$ 0	\$ 50,000
Quality Improvement	\$ 20,000	\$ 4,500	\$ 24,500
General Management	\$ 296,741	\$ 0	\$ 296,741
Functions of DSA	\$ 0	\$ 74,000	\$ 74,000
<b>TOTALS</b>	<b>\$ 1,023,244</b>	<b>\$ 347,903</b>	<b>\$ 1,271,147</b>

## **SECTION VII. ASSURANCES**

Written and signed Assurances were submitted to the Administration on Developmental Disabilities, Administration for Children and Families, United States Department of Health and Human Services, regarding compliance with all requirements specified in Section 124 (C)(5)(A) – (N) in the Developmental Disabilities Assistance and Bill of Rights Act.

The approving official for the Assurances is Spencer Cronk, Commissioner, Minnesota Department of Administration.

The Assurances were sent on July 13, 2011 and received by the Administration on Developmental Disabilities on July 18, 2011.



Andrew M. Cuomo  
Governor  
Courtney Burke  
Commissioner



New York State Office For People With Developmental Disabilities

# Statewide Comprehensive Plan

2012-2016



October 1, 2012

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Dear Friends and Colleagues:

I am pleased to share with you the New York State Office for People With Developmental Disabilities' (OPWDD) Statewide Comprehensive Plan for 2012-2016.

The plan describes OPWDD's strategic direction for carefully and methodically shifting New York's developmental disabilities service delivery system to managed care through the implementation of the People First Waiver. The People First Waiver is significant because New York State will be one of the first states to combine long-term care, physical health and mental health services into a 1915 b/c waiver that will address all the needs of people with developmental disabilities. OPWDD is poised to submit waiver applications and/or waiver amendments to the federal Centers for Medicare & Medicaid Services (CMS) this spring and anticipates having approved agreements by fall 2013.

In addition to our efforts to plan and implement the People First Waiver, OPWDD continues to make progress on system reforms, and implement new approaches to delivering services and supports within our existing Home and Community Based Services (HCBS) waiver. Some of our most recent accomplishments are:

- Reduced the number of people with developmental disabilities who live in institutional settings to just over 1,000 people and through the People First Waiver the census will drop even more significantly.
- Received 1.8 million dollars through the Governor's Medicaid Redesign Team's (MRT) Supportive Housing Development Program, which will increase the number of affordable, integrated, and accessible housing opportunities.
- Implemented Phase II of Community Habilitation so individuals experience greater choice over the meaningful activities that they engage in.
- Improving access to individualized services through the development of a new front door and Individualized Community Services (ICS).
- Creating a culture of transparency and accountability by posting provider performance report cards on the OPWDD website.
- Centralized the oversight of serious incidents and allegations of abuse to safeguard individuals with developmental disabilities.

System transformation is not easy and requires the help of people beyond the exceptional staff at OPWDD. I want to thank the many stakeholders involved on the People First Waiver work teams, the individuals, family members, and advocates who provided input at public engagement events, and voluntary providers that promoted individualized services through the innovative ideas workshops and on other various committees and councils.

Together, we have made significant progress and I look forward to our continued partnership in designing a service delivery system that is equitable, sustainable, and accessible to New Yorkers with developmental disabilities and their families.

Sincerely,

Courtney Burke  
Commissioner

**Executive Office**

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## Mission, Vision, Values, and Guiding Principles

### Mission

We help people with developmental disabilities live richer lives.

### Vision

People with developmental disabilities enjoy meaningful relationships with friends, family, and others in their lives, experience personal health and growth, live in the home of their choice, and fully participate in their communities.

OPWDD is committed to achieving five basic outcomes for people with developmental disabilities:

- **Person First** – Individuals with developmental disabilities have plans, supports, and services that are person-centered and as self-directed as they choose.
- **Home of Choice** – Individuals with developmental disabilities are living in the home of their choice.
- **Work and Meaningful Activities** – Individuals with developmental disabilities are able to work at paying jobs and/or participate in their communities through meaningful activities.
- **Relationships** – Individuals with developmental disabilities have meaningful relationships with friends, family, and others of their choice.
- **Health and Safety** – People with developmental disabilities experience good health and are safe in their home and community.

### Values

**Compassion** – The capacity to appreciate what others think and feel.

**Dignity** – The recognition of the worth of each person and the treatment of individual rights and preferences with respect, honor, and fairness.

**Diversity** – The celebration, respect, and embracing of the differences among us, because these differences strengthen and define us.

**Excellence** – The continual emphasis on innovation, increasing knowledge, and delivering the highest quality supports and services.

**Honesty** – The foundation on which trust is built and truth is communicated.

## **OPWDD's Guiding Principles**

**Put the Person First** – People with developmental disabilities are the heart of everything we do, and this person-first ethic is embodied in the way we express ourselves and in the way we conduct business.

**Maximize Opportunities** – OPWDD's vision of productive and fulfilling lives for people with developmental disabilities is achieved by creating opportunities and supporting people in ways that allow for as many as possible to access the supports and services they want and need.

**Promote and Reward Excellence** – Quality and excellence are highly valued aspects of our services. We find ways to encourage quality, and create ways to recognize and incentivize excellence to improve outcomes throughout our system.

**Provide Equity of Access** – Access to supports and services is fair and equitable; a range of options is available in local communities to ensure this access, regardless of where in New York State someone resides.

**Nurture Partnerships and Collaborations** – Meaningful participation by people with developmental disabilities strengthens us. OPWDD staff and stakeholders create mechanisms to foster this participation. The diverse needs of people with developmental disabilities are best met in collaboration with the many local and statewide entities that are partners in planning for and meeting these needs, such as people who have developmental disabilities, families, nonprofit providers, communities, local government, and social, health, and educational systems.

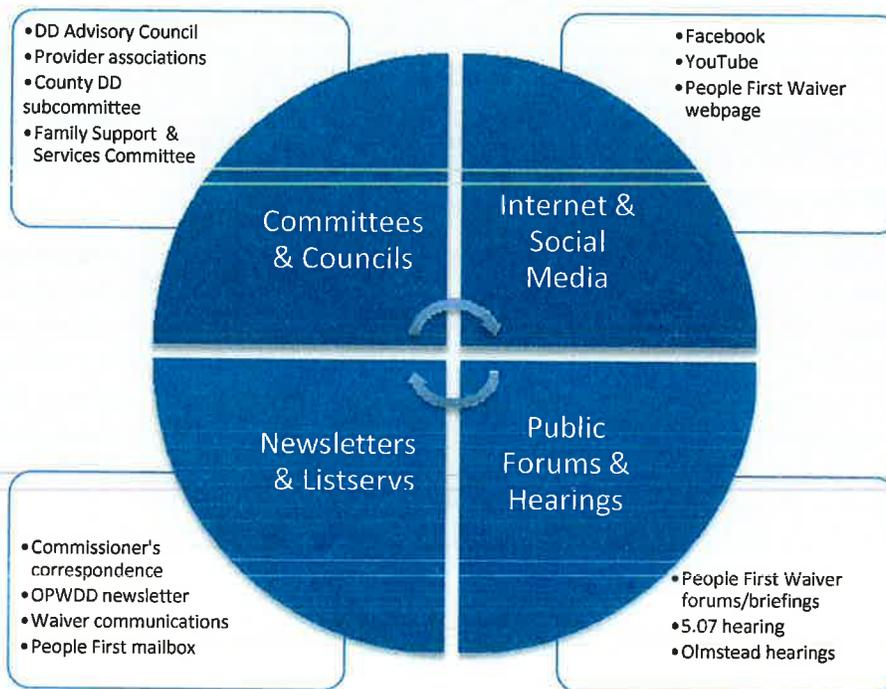
**Require Accountability and Responsibility** – There is a shared accountability and responsibility among all stakeholders, including individuals with developmental disabilities, their families, and the public and private sector. OPWDD and our providers are held to a high degree of accountability in how they carry out their responsibilities. We strive to earn and keep the individual trust of people with developmental disabilities and their families, as well as the public trust. Creating a system of supports that honors the individual's right to be responsible for their own life and accountable for their own decisions is of paramount importance.

## Stakeholder Engagement

OPWDD recognizes that continuous public engagement is an essential element of strategic planning. The quality of the People First Waiver and its impact on the provision of habilitative supports and services is dependent upon feedback from all New Yorkers involved in the developmental disability system. As a result, senior management within the organization regularly meet with the Commissioner's Developmental Disabilities Advisory Council, individuals with developmental disabilities, self-advocates, other advocates, family members, provider associations, county directors, voluntary provider agencies, and other interested parties to ascertain how federal, state, and local policies and procedures affect people with developmental disabilities. Outcomes from stakeholder engagement are incorporated into the agency's statewide comprehensive plan for service delivery.

Traditionally, OPWDD engaged stakeholder groups through formal face-to-face meetings and forums, and recently expanded its presence on the Internet through social media outlets such as YouTube and Facebook. Figure 1 highlights the mediums OPWDD uses to encourage a continuous dialogue with the public.

**Figure 1. Stakeholder Engagement**



Ongoing communications, whether face-to-face or online, help New York State shape the People First Waiver and the many system reforms it will bring. In April 2012, OPWDD held a series of public briefings to update the public on the waiver, answer questions, and gather further input. People First Waiver liaisons from regional offices also began meeting with groups of stakeholders around the state for the same purpose. In spring 2012, OPWDD held innovative ideas workshops that showcased how providers are working together for improved efficiencies and outcomes for the people they support. Guidance and oversight of the People First Waiver and its development and implementation recently transitioned from the steering committee to the standing Developmental Disabilities Advisory Council.

The goal of OPWDD's public engagement efforts is to maintain an open line of communication with key stakeholders and use their feedback to continuously improve the quality of service delivery and plan for the future development of the People First Waiver.

## Environment for Change

In addition to gathering feedback from stakeholders, OPWDD also scans the federal, state, and local environment for regulations, policies, and other changes that will potentially impact services for individuals with developmental disabilities. Although many factors contribute to the transition to managed care and systemic reform, five state and/or federal policy decisions significantly influence the current operating environment and strategic direction:

1. Olmstead decision;
2. Affordable Care Act;
3. Medicaid redesign;
4. Budget/service demands; and
5. Quality oversight.

### Olmstead Decision

The 1999 U.S. Supreme Court ruling in the landmark case of *Olmstead v. L.C.* held that unnecessary institutionalization of individuals with disabilities violates the Americans with Disabilities Act (ADA). The ruling found that individuals should be allowed to receive services and supports in the most integrated setting appropriate to their needs. *Olmstead vs. L.C.* was initiated on behalf of two individuals in Georgia who were confined in a state psychiatric hospital long after their treatment team had recommended they could be served effectively in the community. Their unnecessary institutionalization was interpreted as discrimination by reason of disability.

To meet their obligations under the ADA, states must demonstrate they have an effective plan to transition eligible individuals with developmental disabilities to integrated community settings. Early in his tenure, Governor Andrew M. Cuomo reiterated his commitment to civil rights and the ADA in his State of the State address in January 2012 when he charged his agency commissioners to develop an Olmstead Plan.

“As the Supreme Court ruled in *Olmstead v. L.C.*, people with disabilities have the right to receive care in the most integrated setting appropriate to their needs. Therefore, we will develop an Olmstead implementation plan that will guide the transition of

individuals from institutional to community-based care, provide access to affordable and accessible housing, and promote employment of persons with disabilities. We must erase stigmas and ensure that the rights of people with disabilities are fully recognized and fully protected.”

—Governor Andrew M. Cuomo

As a first step, OPWDD is working with Governor's Cuomo's office and the other state health and human service agencies to gather input from the public and develop a comprehensive plan for providing services and supports in the most integrated setting. In late summer and early fall of 2012, Governor Cuomo sponsored four public hearings to solicit information from people with disabilities and other stakeholders. Testimony from the public hearings is being analyzed and will be used to develop the outline and content of the Olmstead Plan. Preliminarily, the outcomes from the hearings have been summarized into a few target areas for the developmental disability system. To support consistency with the Olmstead Decision, OPWDD supports:

- Transitioning individuals residing in developmental centers to community-based settings by 2014;
- Preventing institutionalization by helping individuals access community-based supports and services, including, but not limited to, community habilitation, care coordination, behavioral interventions, environmental modifications, and adaptive equipment;
- Creating a valid and reliable assessment process to determine the appropriate level of support and funding individuals need to live and work in the community;
- Increasing the number of individuals employed in integrated settings and earning minimum wage or higher;
- Developing affordable, accessible, and integrated housing opportunities with the appropriate level of support needed for individuals; and
- Collaborating with other state and local systems to address transportation barriers in rural, suburban, and urban settings.

New York State will further refine its goals and strategies, and then publish the final comprehensive, working Olmstead Plan by May 2013.

At the federal level, the Olmstead Decision and the ADA set the policy direction for all state governments to serve qualified individuals with disabilities in the most integrated setting appropriate to their needs. OPWDD is committed to achieving this outcome with the People First Waiver being the vehicle for state change.

### **Affordable Care Act**

As the Olmstead Decision conceptualizes how states should best serve individuals with disabilities, the Affordable Care Act establishes new policies and incentives for states to expand access to Medicaid Home and Community Based (HCBS) Services programs. On March 23, 2010, President Obama signed comprehensive health reform: the Patient Protection and Affordable Care Act, into law. The ACA contains provisions to expand coverage, control health care costs, and improve the health care delivery system. This legislation will impact all Americans, including individuals with developmental disabilities. Specifically, individuals with disabilities in New York State will benefit from the following reforms and protections:

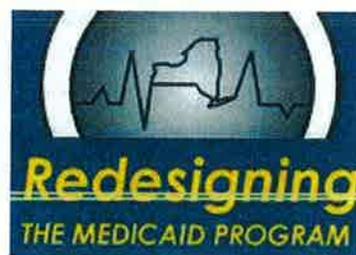
- Health coverage for all individuals regardless of disability or pre-existing conditions;
- Prohibits annual coverage limits in health plans and insurance policies;
- Requires health benefit plans to include rehabilitative and habilitative services and devices as covered benefits;
- Expands Medicaid eligibility to 138% of the federal poverty level (approximately \$30,000 per year for a family of four);

- Creates a temporary 90% federal match for states to provide health homes for individuals with chronic conditions;
- Provides states with the option to expand community-based attendant services through Community First Choice (CFC); and
- Extends the Money Follows the Person (MFP) rebalancing demonstration through September 30, 2016.

The ACA will help many individuals with developmental disabilities receive better coverage through the private insurance industry. In addition, the New York State Department of Health (DOH) is participating in the Community First Choice option, which will expand participant directed and agency-based attendant care supports as part of the Medicaid state plan. OPWDD is participating in the development of CFC, which will be a viable alternative to institutional settings for seniors and people with disabilities.

### **Medicaid Redesign**

Governor Andrew M. Cuomo established the Medicaid Redesign Team (MRT) by executive order upon taking office in January 2011, bringing together stakeholders and experts from throughout the state to work cooperatively to reform the Medicaid system and reduce costs. The most significant aspect of this initiative is the transition of all Medicaid programs to managed care, resulting in New York State pursuing the People First Waiver. In addition, the Governor's MRT identified supportive housing as one of its priorities. In March 2012, the Governor's budget established and funded a new supportive housing development program that provides service funding, rent subsidies, and capital dollars to create supportive housing for Medicaid recipients. OPWDD was awarded \$1.8 million for this effort. More information about this program is discussed in the housing section.



### **Budget/Service Demands**

Many people with developmental disabilities are living longer to the point where lifespans are nearly comparable to that of the general population. Analyses conducted at OPWDD demonstrate that the proportion of individuals with multi-system and complex health needs is growing and will continue to grow well into the future. Individuals seeking services are increasingly likely to have a dual diagnosis (30%), autism spectrum disorder (20%), and two or more medical conditions (20%). Statewide, OPWDD is also noticing growth in federally recognized racial/ethnic minority groups accessing services (36%), illustrating the need for providers to become increasingly culturally and linguistically competent.

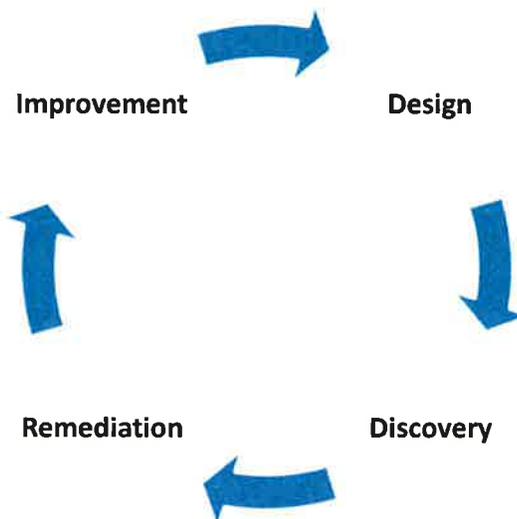
As the demographics of individuals in New York State change, so do their requests for specific service and support models. People with developmental disabilities and their families are increasingly seeking more individualized services that provide supports in their own home and promote community participation. Currently, over 80% of OPWDD's community funding is tied

to certified residential and day services, which occur in congregate settings. Given the high proportion of funding associated with group-based, residential, and day services will play a central role in efforts to contain growth in future expenditures. Efficient and effective models of care that continue to meet individual's needs must be promoted. OPWDD outlines strategies in the People First Waiver section of this report to expand individualized services and ensure the fiscal health and long-term longevity of the developmental disabilities service system.

### Quality Oversight

OPWDD continues to implement quality oversight reforms to improve the quality of supports and services provided to individuals with developmental disabilities. Quality improvement is not a single goal that is achieved at one specific point in time, but a process of implementing change, monitoring outcomes, and then addressing issues as they arise. OPWDD follows the Centers for Medicare & Medicaid Services' (CMS) model for continuous quality improvement (CQI) for HCBS waivers, as shown in Figure 2.

**Figure 2. Continuous Quality Improvement Model**



The CQI model is used for OPWDD's existing HCBS waiver and will be adopted as the quality improvement framework for the People First Waiver. CQI uses empirical data to propagate continuous improvement in a cyclical fashion. This model has been used in various sectors, including health and human services.

The CQI process is as follows: first, OPWDD designs a plan to monitor the quality of the services and supports provided to individuals with developmental disabilities. Next, staff engage in a discovery process to examine the efficacy of the service delivery system through

the use of quantitative data. Then, based on the data collected and staff observations, OPWDD determines which aspects of the system require remediation or correction. Finally, the agency implements improvements to the developmental disabilities system to ensure people are healthy, safe, and receive quality supports and services. CQI allows for consistent, ongoing monitoring of service delivery practices in New York State, with a focus on improving quality of life for individuals with developmental disabilities.

**“The Justice Center for the Protection of People with Special Needs will give New York State the strongest standards and practices in the nation for protecting those who are often the most vulnerable to abuse and mistreatment.”**

**– Governor Cuomo**

In addition to CQI, OPWDD has been participating in statewide, interagency quality oversight initiatives including working diligently to prepare for the implementation of the Justice Center and other changes necessary to conform with this historic piece of legislation taking effect on June 30, 2013.

# System Transformation

## Cultural Change Initiative

The initiative to reshape the culture of OPWDD and the state's developmental disabilities system began in earnest in fall 2011 with the creation of a workgroup comprised of leaders from state and voluntary agencies, self-advocates, families, and direct support professionals. Culture is defined as a shared set of attitudes, values, goals, and practices that characterize the developmental disabilities system. The attributes of culture that OPWDD is seeking to develop throughout the statewide system are:

- Strong, committed, and caring;
- High-performing and based on the agency's core values of compassion, dignity, diversity, excellence, and honesty;
- Fostering relationships based on trust and confidence in the service system;
- Creating a learning environment of ongoing assessment and improvement; and
- Providing clear understanding to all members of the service delivery system of their roles and responsibilities in building and sustaining this culture.

Creating lasting changes in culture requires an alignment of organizational values and policies, as well as alignment of personal values held by employees throughout the system. To support the creation of the desired culture, OPWDD is undertaking initiatives spanning four major areas: leadership's decision-making, policy, and structure; workforce and talent development; work processes and systems; and quality improvement.

As of summer 2012, the workgroup defined goals and focus areas for multiple agency initiatives. These include: OPWDD's adoption of the National Alliance for Direct Support Professionals' Code of Ethics; core competencies for DSPs, and core competencies for DSP supervisors in progress; a new system-wide standard for service provision called Positive Relationships Offer More Opportunities to Everyone (PROMOTE) that focuses on positive approaches to supporting individuals, including behavior intervention and a reduction in use of physical restraints; a shift to a person-centered service delivery model under the People First Waiver; an agency reorganization to create consistency in practice and maximize efficiency; and improved service delivery.

OPWDD is implementing these initiatives in a coordinated manner to serve as levers to shape culture and the statewide system of supports.

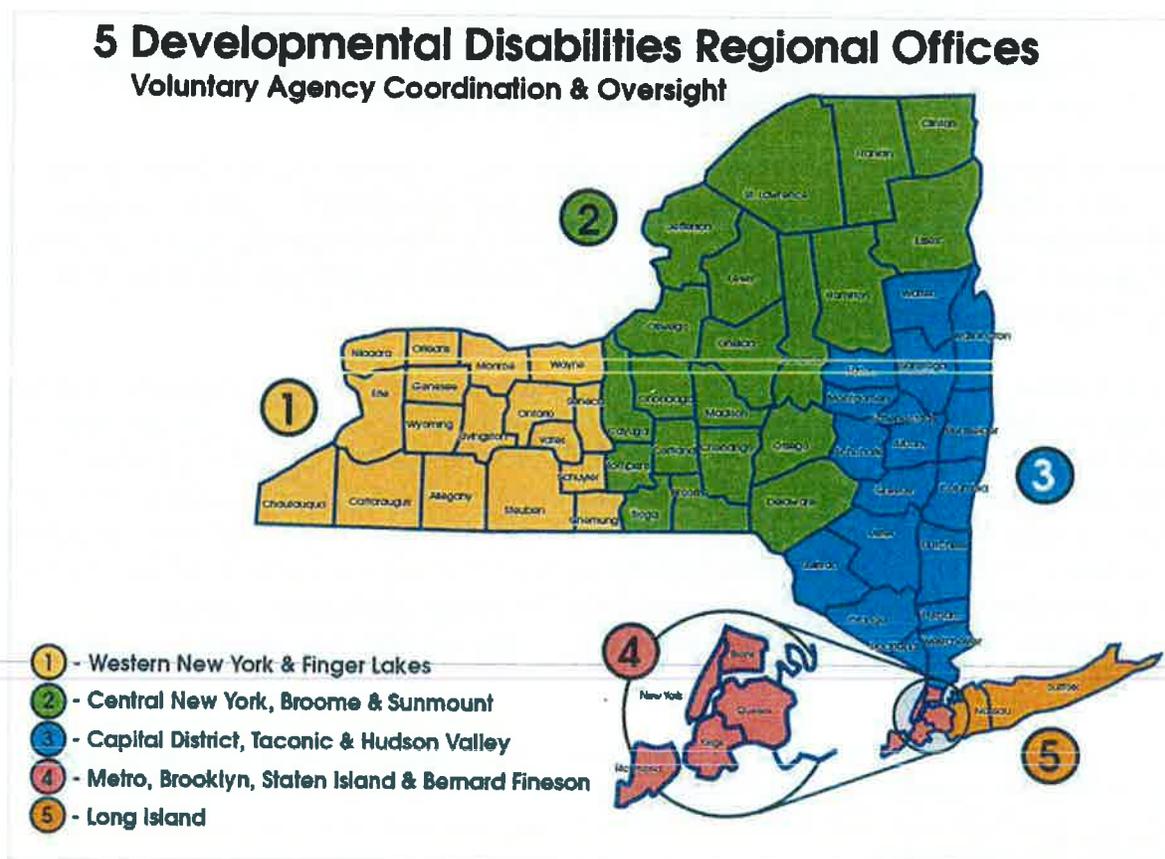
## OPWDD Reorganization

The goal of OPWDD's reorganization is to implement a consistent approach and culture to all developmental disabilities services (whether provided by the state or voluntary agencies) so that any individual who receives supports can expect the same quality and positive environment no matter what they need, where they are located, or which agency supports them.

The developmental disabilities services offices (DDSOs) were formed in 1978 to create regions that focused on transitioning large campus populations into community settings. By 1995, nine developmental centers had closed, and the original 20 DDSOs were consolidated to 13. This structure was in effect until OPWDD reorganized in July 2012.

In OPWDD's new organizational structure, the oversight of voluntary providers and state operations is divided into two distinct but coordinated offices, state operations offices and regional offices, under the Division of Service Delivery. Five regional offices are responsible for overseeing voluntary agency coordination and monitoring. Because voluntary agencies account for approximately 80% of OPWDD's service provision, it was important for regional offices to focus on this segment of the system. The catchment areas of the regional offices were established to improve oversight and quality improvement, as well as to allow for cross system collaboration among State agencies. Figure 3 shows the five developmental disabilities regional offices (ROs).

**Figure 3. Regional Offices**



OPWDD reorganized its state operated programs into six state operations offices (SOOs). The sole responsibility of the SOOs is the operation and oversight of residential, day service, clinic, and other programs for which New York State is the direct provider of service or provider of record. The six state operations offices combine the former DDSO catchment areas into the following model shown in Figure 4.

Figure 4. State Operations Offices



The purpose of the reorganization was to bring a clearer focus to these two important and distinct aspects of OPWDD’s service system. For decades, the DDSO directors assumed responsibility for state-operated supports, in addition to local operations, which included all local administrative and support functions (e.g., safety/security, maintenance, human resources, business office operations, staff development and training, and IT), as well as local voluntary agency provider development and coordination. This diverse set of duties was challenging to manage under the DDSO model. The new framework will provide a consistent approach and culture, so that individuals and their families can expect quality in all services delivered by OPWDD and its voluntary provider partners.

## Putting People First

### People First Waiver

In the summer of 2012, OPWDD entered into the implementation planning stage to finalize the People First Waiver application and carefully map the transition to managed care. The agency established targeted work teams composed of individuals with developmental disabilities, family members, providers, and local government units to focus on three key design areas of the new service delivery system: 1) access, enrollment, and advocacy; 2) care coordination; and 3) modernizing the fiscal platform.

The **access, enrollment, and advocacy work team** recommended policies and procedures for the pilot managed care organizations known as developmental disability individual support and care organizations (DISCOs) that will:

- Ensure DISCOs inform people with developmental disabilities about their individual rights as DISCO enrollees, including rights related to the grievance and appeals process;
- Evaluate grievance and appeals practices at DISCOs to ensure effective enrollee due process protections; and
- Provide individuals with access to strong independent advocacy.

The **care coordination work team** developed quality measures in collaboration with Delmarva, a consultant group with experience in formulating quality outcomes in other states, and outlined the parameters for a customized and integrated care management/care coordination system that employs person-centered planning to support the full range of service needs for people with developmental disabilities. The team made recommendations regarding:

- Required qualifications and core competencies for the lead care coordinator;
- Quality outcome measures for care coordination; and
- Person-centered planning, documentation, training, and supervision.

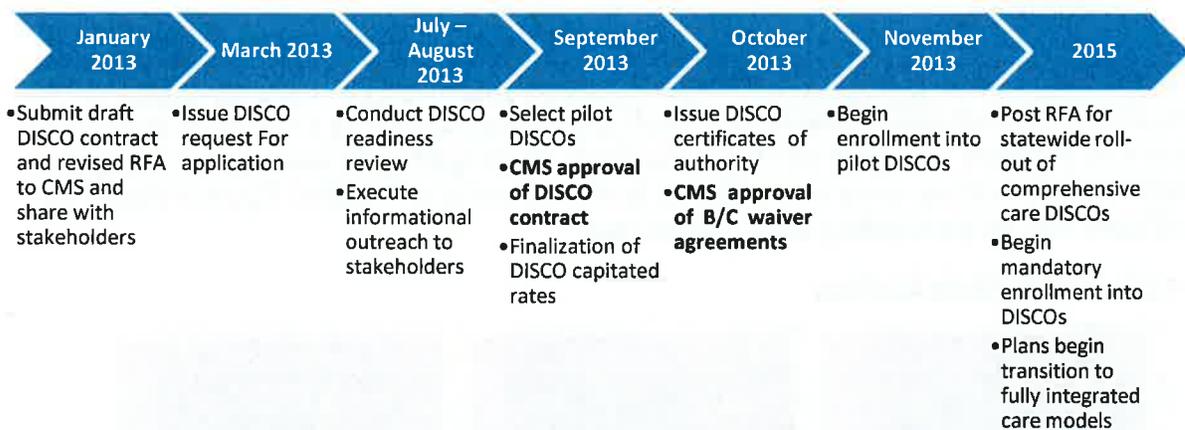
The **modernizing the fiscal platform** team was charged with providing a foundation for a new rate reimbursement system that will promote equity, sustainability, alignment of the financial platform, and incentives for desired service and system outcomes for people with developmental disabilities.

The fiscal platform team agreed that OPWDD's rate reform should follow a component-based approach that examines cost patterns for various rate components (e.g., program support, general and administrative costs) as they relate to the direct care staff wage. This approach is used to establish the total cost of a direct staff hour, and then to determine standard fees according to the number of staff hours needed to meet an individual's needs. This method of standardized rate development, based on the direct care staff driven model has been used in other states. OPWDD has engaged consultants that are experienced in this approach both for long-term care programs and for developmental disabilities services. It is OPWDD's intent that the new methodology will be implemented in the fee-for-service delivery system and also used in the development of a capitation fee within managed care.

The targeted work teams of the People First Waiver completed their work in fall 2012. OPWDD posted their final recommendations of the work teams on the People First Waiver webpage: [www.opwdd.ny.gov/opwdd\\_services\\_supports/people\\_first\\_waiver/targeted\\_work\\_teams](http://www.opwdd.ny.gov/opwdd_services_supports/people_first_waiver/targeted_work_teams).

Key elements of the work teams' recommendations will be incorporated with revisions to the draft request for applications (RFA) that will be submitted to the federal Centers for Medicare & Medicaid Services (CMS) as part of the 1915 b/c People First Waiver applications. Working with the New York State Department of Health, OPWDD expects to submit the draft DISCO contract to CMS in January 2013 and anticipates final approval by September 2013. Once the applications are submitted, OPWDD will post links to the CMS website, where stakeholders can access the waiver applications and provide formal comments. Figure 5 shows the timeline for the implementation of the People First Waiver through 2015.

**Figure 5. People First Waiver Timeline**



To help service providers prepare for system reforms, OPWDD posted a draft of the RFA for *informational purposes only* on its People First Waiver webpage ([www.opwdd.ny.gov/opwdd\\_services\\_supports/people\\_first\\_waiver/home](http://www.opwdd.ny.gov/opwdd_services_supports/people_first_waiver/home)) for DISCOs.

**People First Waiver Case Studies**

From November 1, 2012 through December 31, 2013, the People First Waiver case studies will enable OPWDD and its provider network to pilot key system reforms before moving to a managed care environment. By focusing on small pilot projects, OPWDD and its participating providers will gain valuable experience to help the transition to a managed care delivery system that addresses the unique needs of people with developmental disabilities.

The design of the case studies will concentrate on three major areas:

1. **Assessment:** OPWDD will test the tools, processes, and results of the coordinated assessment system (CAS). The CAS will be built from the InterRAI assessment suite, which can predict individual support needs and convert assessment information into an individual life plan (i.e., care plan). The life plan identifies personal goals and health and safety supports needed by the person.

2. **Translate flexible financing (within existing authority and resources) to demand oriented, innovative support models:** OPWDD will use existing resources to flexibly fund innovative services and supports based on what people with developmental disabilities really need and want. The case study utilizes current support options within the 1915(c) waiver to maximize access to self-directed supports. In addition, it will provide an important learning opportunity for providers to develop strategies that support personal outcomes while transitioning to a funding structure that is equitable and needs-based.
  
3. **Individual outcome measures and quality performance:** OPWDD will develop and pilot new approaches to assess provider performance, an indicator of quality in developmental disabilities systems. This approach incorporates the InterRAI, person-centered life plan outcomes and case study documentation, the National Core Indicators (NCI) consumer survey, and other tools that measure the extent to which providers are helping people with developmental disabilities identify and accomplish their individual outcomes.

To test these concepts, OPWDD will work with voluntary agencies that have been identified as exceeding minimum quality standards through special accreditation as a Compass agency or that have practices consistent with these standards, by completing focused studies that gather data about several key areas where change is needed and/or anticipated. Figure 6 shows the providers that are participating in the case studies.

**Figure 6. Case Study Agencies**



In addition, OPWDD is partnering with other stakeholders to gain objective input into both the design and lessons learned from the studies. The following organizations will help test some of the key elements in the case studies:

- **Westchester Institute for Human Development (WIHD):** WIHD created an iPad application to measure consumer satisfaction and individual outcomes largely based on NCI criteria. The application is interactive so individuals with disabilities can provide responses to survey questions with minimal assistance from a proxy. WIHD is refining the application so it can be tested with case study participants.
- **Self-Advocacy Association of New York State (SANYS):** SANYS will work with WIHD to facilitate the use of the iPad application by individuals receiving services. Self-advocates will provide instruction on the application for independent use of the iPad or work with the person to give direct assistance, if needed.
- **Council on Quality and Leadership (CQL):** CQL will provide training about determining personal outcome measures for people participating in the studies. The training and personal outcome measure (POM) workshops will be for representatives from participating agencies, families, and OPWDD's Division of Quality Improvement (DQI) and other staff. The approaches in the CQL curriculum are evidence-based and used nationally as appropriate measures of assessing outcomes for people with developmental disabilities.
- **New York State Developmental Disabilities Planning Council (DDPC):** DDPC will work with OPWDD to monitor and provide feedback on the joint quality activities during the case studies. Through DDPC support, OPWDD will involve family representatives in the CQL POM workshops.
- **InterRAI:** OPWDD is partnering with InterRAI, an international consortium of assessment developers, to create a core assessment instrument with appropriate supplemental tools to quantify the needs of individuals receiving supports and services. The CAS will be utilized in the case studies and surveys related to the process and adequacy of information will be conducted. The information collected (related to both the assessment process and the tools) during the case studies will be reviewed by InterRAI and OPWDD for feedback on changes needed to achieve a comprehensive and person-centered assessment system.

### **Case Study Participants**

A group of individuals now served by providers in the general case study will be selected as focused case study participants. The focused case study participants are aligned in the following categories:

- Individuals with developmental disability profiles (DDPs) that indicate they have independent skills and are living in a 24/7 certified residential setting.
- Individuals with DDPs that indicate high behavioral needs, but are receiving few to no OPWDD services.
- Individuals identified by case study provider agencies as wanting alternative supports such as increased self-direction, intensive employment services, and other alternative models of support.

The participating providers serve a total of 12,800 people. OPWDD estimates that there will be approximately 4,700 individuals in the general case study, and of these, approximately 1,000 will participate in the focused case studies. OPWDD has selected 750 people to participate in the two focused case study groups based on the DDP analysis and will select an additional 250 case study participants who request alternative supports.

### **Case Study Learning Objectives**

The success of People First reforms is predicated on building an innovative and flexible infrastructure that supports the diversity of all individuals with developmental disabilities. This infrastructure must perpetuate care coordination practices that are effective across a variety of living environments; be based on evidence-based clinical practices, utilize person-centered innovative models of support with flexible funding; and employ quality measures that tie to personal outcomes. OPWDD hopes to meet the following learning objectives as a result of implementing the case studies:

#### **1. Assessment:**

- How well the assessment process and tools were able to predict individual support needs and translate them into an effective person-centered life plan with measurable individual outcomes.
- Best practices for efficiency and inter-rater reliability of the assessment process.
- Best practices for conducting the assessment with the least amount of intrusiveness with the involved parties (people being assessed, family, and support givers).
- Best practices to ensure that assessment specialists have sufficient input into the process and that providers receive sufficient information to develop a comprehensive person-centered plan.
- Delineation of the training needs and qualifications to successfully utilize the InterRAI.

#### **2. Translate flexible financing (within existing authority and resources) to demand oriented, innovative support models:**

- Identification of planning approaches and innovative strategies and support models in a self-directed environment.
- Whether individuals accessed different community-based housing support models.
- Whether individuals in 24/7 certified housing models were able to transition to more integrated settings.
- Whether service changes led to better outcomes and increased individual satisfaction.

#### **3. Individual outcome measures and quality:**

- How well each provider met individual needs and desired outcomes.
- Whether the case study care plan and service documentation capture an individual's needs and identify the person's outcomes for accurate quality review. How individual quality measurement can translate into a core set of specialized managed care quality performance measures specifically for people with developmental disabilities.

## DISCO Pilots

OPWDD is committed to the mission of helping people live richer lives and creating stronger person-centered services now and in the future for individuals with developmental disabilities. Over a two-year period, OPWDD, with the support and oversight of DOH, will pilot specialized managed care organizations that meet the applicable requirements of Article 44 of the Public Health Law and have expertise in the provision of services under the auspice of OPWDD. As previously mentioned, these new entities, charged with coordinating comprehensive supports and services under new Medicaid funding agreements with the federal government (referred to collectively as the People First Waiver) will be known as developmental disabilities individual supports and care coordination organizations (DISCOs).

Key elements of DISCOs will include:

- Receiving funds, providing person-centered planning, coordination of services, and ensuring delivery of high quality services.
- Funding to the DISCO will be based on an individual's needs, not allocated based on general service categories.
- Managing per-member-per-month funds to meet the needs of all their members.
- No limit for spending on any individual—the capitated rate (i.e., specific payment made to the DISCO as designated by Medicaid) will *not* mean limited services. An individual must have a service plan that meets his or her needs, regardless of cost.

During the pilot period, individuals will voluntarily opt to enroll in the pilot DISCO. In keeping with the programmatic objectives of the People First Waiver, the DISCO will be required to describe how it will:

- Provide person-centered planning for all individuals enrolled in the DISCO;
- Promote living and active engagement in the most integrated setting;
- Ensure that each individual who chooses to do so can self-direct his or her services, including the option for budget and employer authority; and
- Promote paid employment for individuals enrolled in the DISCO.

The application process will begin in 2013 and will include a letter of intent, a formal application, and a final readiness review that ensures that the DISCO is ready to begin coordinating services. In order to be eligible to become a DISCO, an applicant must be a public or nonprofit (private) entity incorporated under New York State Law and have at least 10 years' experience coordinating care for individuals with intellectual/developmental disabilities. Experience coordinating care for individuals with developmental disabilities will be evaluated based on the average number of years of experience of the DISCO's board members and officers in overseeing and operating entities that deliver Medicaid service coordination or HCBS waiver services, and are in good standing with OPWDD.

The DISCO and all network providers with which it subcontracts will be in compliance with all applicable state and federal licensing, certification, and other requirements. These entities must be generally regarded as having a good reputation and have demonstrated capacity to perform needed services.

The DISCO must maintain an administrative and organizational structure that supports high quality supports and services through comprehensive care coordination. The management structure should ensure effective linkages among administrative areas: quality management;

network development and contracts management; information technology (i.e., utilization review); enrollment/disenrollment; care coordination; accounts receivable/accounts payable; and budget, finance, and accounting. A complete description of a DISCO's areas of responsibility will be identified in its contract with New York State.

Key elements of the transition to managed care service delivery include:

- Protecting due process rights and independent advocacy.
- DISCOs will be required to serve people with all levels of service need—no DISCO may drop people with higher service costs.
- Everyone will have a choice of providers within their DISCO.
- Every person will have the option to self-direct an individualized service budget with the appropriate level of support.
- Transition to a managed care service system across the state will take place slowly over many years and begin with carefully constructed and evaluated pilot DISCOs.
- OPWDD will ensure that people can continue to use their current service providers during DISCO rollout.

### **Dual Eligible Individuals Demonstration**

New York State DOH's duals demonstration is a proposed initiative to coordinate Medicare- and Medicaid-funded physical health care, behavioral health care, and long-term supports and services. A limited number of individuals (up to 10,000) with developmental disabilities will have the option to voluntarily participate in this demonstration. OPWDD participation will occur in two phases:

- Phase 1: Starting in July 2013, OPWDD, working through DOH, will approve up to three managed long-term care plans (MLTCPs) to provide non-OPWDD long-term supports and services (e.g., personal care, adult day care, etc.).
- Phase 2: Starting in January 2014, these plans will transition to Fully Integrated Duals Advantage (FIDA) programs that will provide comprehensive services and supports (i.e., OPWDD long-term supports, health care, behavioral health care, and the Phase One long-term supports).

The demonstration will allow OPWDD to begin operating a comprehensive managed care model on a small scale prior to statewide transition. The demonstration application and additional information about submitting public comment on the proposal may be found at:

[www.health.ny.gov/health\\_care/medicaid/program/medicaid\\_health\\_homes/dual\\_demo\\_proposal\\_to\\_cms.htm](http://www.health.ny.gov/health_care/medicaid/program/medicaid_health_homes/dual_demo_proposal_to_cms.htm).

### **Individual and Community Supports and the Front Door**

The Individualized Services Workgroup, which convened in late 2011, was charged with helping OPWDD create immediate mechanisms for consistent, streamlined, statewide access to individualized service options prior to full implementation of the People First Waiver. The workgroup and its subcommittees worked through the spring of 2012 to develop the recommendations that are the basis and hallmarks of Individual and Community Supports (ICS).

ICS is a person-centered approach to developing plans of support for people; it is not a program or service. ICS is consistent with the direction and structure of the People First Waiver in that it

is based on:

- Person-centered practices;
- More informed choice of supports and services;
- Combined use of paid and natural community supports;
- Statewide consistency in funding and availability of individualized and self-directed service options; and
- Quality oversight for all individuals receiving services.

ICS will be the way eligible individuals and families seeking OPWDD services access those services. In concert with the goals for the People First Waiver, the ICS philosophy and processes:

- Are driven by the needs of individuals, rather than the services that are currently available;
- Allow individuals as much authority as they and/or their families and circle of support want regarding the supports and services they receive and who delivers those services;
- Provide a streamlined process, plan, and budget to simplify access to and support participation in individualized services, and to facilitate portability of funding; and
- Offer a full array of housing and employment options to encourage individuals seeking services to live and work in their communities of choice.

ICS will be implemented in three phases:

- Phase 1: Begin with new people entering the OPWDD system (September 2012).
- Phase 2: Consolidate all individualized services now offered by OPWDD:
  - Consolidated Supports and Services (CSS)
  - Portal initiative and portal-like plans
  - Learning Institute
  - Individual Supports and Services (ISS), i.e., housing subsidies
- Phase 3: Expand to include individuals currently being served who want to access services in a less restricted setting.

The OPWDD Front Door is defined as the philosophy, criteria, processes, and procedures that are applied consistently to all individuals seeking supports and services through OPWDD's service system in any OPWDD region. The Front Door is a person-centered approach that:

- Moves the service system from a supply oriented to a demand orientated system, where the services system is driven by the needs of individuals rather than by services currently available within agencies;
- Supports informed choice and portability where funding follows the person;
- Facilitates innovative and creative support options;
- Provides consistency and transparency (i.e., clear criteria and processes);
- Ensures equity where similarly situated individuals have the same access to supports and services based on consistent criteria and needs assessment tools. The process and procedures for access to, and availability of, ICS services will be consistent and fair across all regions of the state; and
- Ensures consistent quality oversight for all in individualized services, and demands a continuous quality improvement appraisal to determine how we are doing and where

improvement is needed.

Planning and design of ICS and the new Front Door began in summer 2012, starting with information sessions for regional office staff; voluntary provider agencies, including the provider associations; Medicaid service coordinators and brokers; and individuals and families. Training sessions on the ICS process, budget template, and policies and guidelines began in August 2012 for the same groups. Training continued through the fall of 2012 and implementation of the ICS plan/budget and the new Front Door process is anticipated for the beginning of 2013.

### **Goal**

People with developmental disabilities have plans, supports, and services that are person-centered and as self-directed as they choose.

### **Outcomes**

- Implement a valid assessment process for individuals with developmental disabilities.
- Establish a cadre of qualified providers that will become DISCOs.
- Implement ICS policies to support statewide access to individualized services and use of individualized, noncertified service options.

### **Performance Measures**

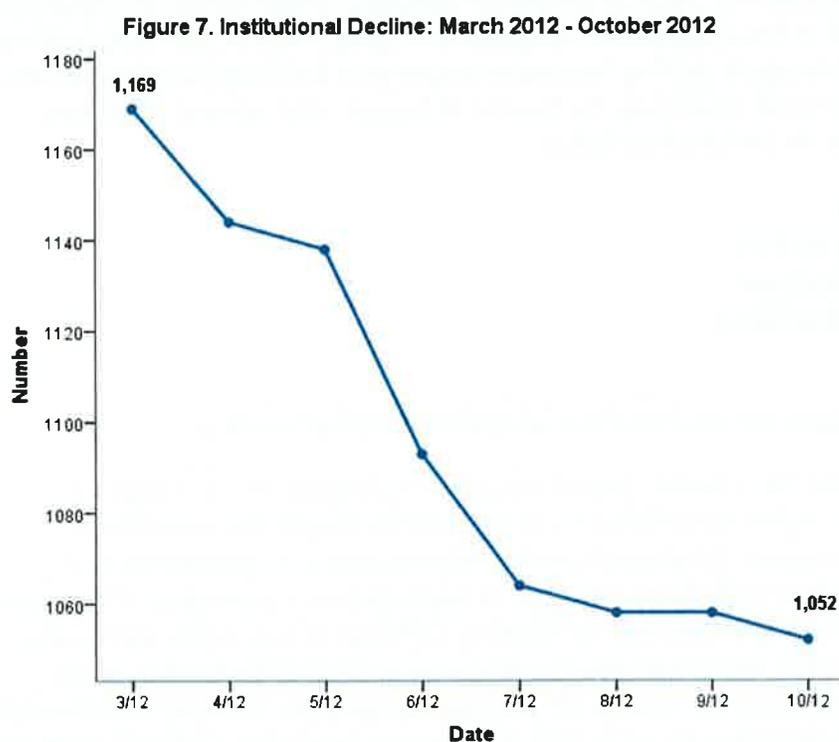
- Number of individuals who participated in the pilot CAS.
- Availability and choice of qualified DISCOs in New York State.
- Statewide growth in the utilization of individualized, noncertified service and support options (such as supportive housing and generic community services for volunteerism and other meaningful activities) by individuals already receiving supports and services and those new to the OPWDD service system.
- Increase in the number of individuals who self-direct their services.
- Individuals with developmental disabilities who access person-centered services express satisfaction with their supports and services.

## Implementing the Mission and Vision

### Home

#### Developmental Center Closure

2012 marks the 25th anniversary of the closing of the Willowbrook Developmental Center and the beginning of a movement that enabled individuals with developmental disabilities to transition out of institutions and into the community. The state began transitioning people with developmental disabilities in the late 1970s when 20 state institutions housed nearly 30,000 people in New York State. Since then, more than 6,200 community homes have been developed, and 13 institutions have closed their doors. As of October 2012, only 1,052 people continue to receive institutional care. Figure 7 highlights the institutional decline since March 2012.



OPWDD is keeping its commitment to close institutions and create new community opportunities. This was demonstrated with the 2011 closure of the West Seneca Developmental Center and the closure of the Staten Island Multiple Disabilities Unit in June 2012.

OPWDD has also announced that the Finger Lakes and Wassaic campus-based residential programs will close by December 2013. As part of OPWDD's discussions with the Center for Medicare & Medicaid Services on the People First Waiver and future system of supports and services for people with developmental disabilities, the expectation is that institutional capacity will total approximately 150 and be considered a time-limited high intensity service. While some individuals will continue to need intensive supports on an interim basis in campus-based settings, people can, should, and do have the right to live and receive their supports and

services in the most integrated community setting possible.

OPWDD's commitment to supporting individuals in the community will assist the transition of an additional 63 people by the end of 2012. As the developmental center census declines, OPWDD will continue to expand the number of appropriate living options for individuals with developmental disabilities through various housing initiatives.

## **Housing Initiatives**

### **Continuum of Housing Options**

OPWDD is fulfilling its obligations under the ADA and Olmstead decision by developing successful strategies to assist people to live in the least restrictive residential environment possible. To accomplish this goal, OPWDD conceptualized a continuum of housing opportunities to ensure that as institutions decline and a vast statewide system of community services increases, there would be a range of residential options available based on individual needs and abilities, instead of the availability of congregate program models. OPWDD facilitated housing forums to learn more about existing housing arrangements that could meet the needs of individuals with developmental disabilities. By the end of August 2012, almost 1,500 had individuals attended forums on the following topics:

- Supportive housing
- Housing options for seniors
- Rural housing development
- Family care and shared living
- Assistive living

### **New York State Housing and Community Renewal (NYSHCR) Partnership**

OPWDD recognizes the need for a sustainable infrastructure to expand the continuum of housing opportunities; from individualized housing in the community with few supports to certified housing with 24/7 support. An array of housing options does not currently exist to sufficiently address the needs of individuals who wish to have control or ownership of their own home or apartment. To further meet this need for housing, OPWDD formed a new partnership agreement with NYSHCR which will include specific language in NYSHCR's funding round starting in 2012. These applications for funding will propose a preference in tenant selection for people with developmental disabilities for up to 10% of a project's total units. Provider applicants must have firm commitments from OPWDD for operating supports and services funding, and development financing for special needs units. Six providers of supports and services to people with developmental disabilities have submitted applications to NYSHCR for early award funding. OPWDD will develop a sustainable infrastructure to seek ways to possibly support these agencies' projects.

### **Housing Counseling**

OPWDD was awarded funds by the U.S. Department of Housing and Urban Development (HUD) in 2012 to strengthen its housing counseling curriculum. OPWDD's downstate housing office is in the process of developing an education and training curriculum for statewide distribution. The training will help individuals develop the appropriate skills to reside in the community. OPWDD seeks to have a cadre of trained housing coordinators and housing

specialists at each of its developmental disabilities regional offices, and its developmental disabilities state operations offices to help people with developmental disabilities understand the pros and cons of living in a less restrictive environment.

### **Supportive Housing Development Program**

OPWDD was awarded \$1.8 million to participate in a new supportive housing development program under the Medicaid Redesign Team's rental subsidies/services programs. OPWDD will utilize a portion of available funds to assist people to live in apartments with ISS rent subsidies and community habilitation, CSS residential settings, and assist some individuals to move from a 24/7 voluntary-operated individualized residential alternative (VOIRA) to settings with less than 24/7 staffing.

OPWDD will match the \$1.8 million which, when combined, will provide opportunities to 180 people with intellectual and developmental disabilities to move into less restrictive residential settings. A request for services (RFS) has been developed, which is designed to spread this initiative throughout New York State.

### **Senior Housing Opportunities**

To create more housing and other options to support the growing cohort of people with developmental disabilities who are aging, OPWDD is researching ways to assist individuals who want to retire from services. OPWDD has engaged the Center for Excellence in Aging at the University at Albany, State University of New York; the State Office for the Aging; and the Department of Health, to learn about residential opportunities that exist and those that may be created for people with developmental disabilities.

In addition to these new housing initiatives, OPWDD continues to implement the following programs to make home ownership and integrated housing a viable option for New Yorkers:

- Home of your Own program;
- Foreclosure prevention services;
- Assets for Independence/Individual Development Account/Match Savings program;
- Home Owner Transit Use Incentive program; and
- U.S. Department of Agriculture Rural Development Single-Family Housing.

More information about these specific programs is available on the OPWDD website: [www.opwdd.ny.gov/opwdd\\_community\\_connections/housing\\_initiative](http://www.opwdd.ny.gov/opwdd_community_connections/housing_initiative).

### **Goal**

People with developmental disabilities are living in the home of their choice.

### **Outcomes**

- Individuals live in the least restrictive residential setting that is appropriate to their needs and abilities.
- Individuals will have a greater continuum of housing supports available in the community.
- OPWDD institutional capacity will drop to approximately 150 (over the next four state fiscal years with time-limited stays).

## **Performance Measures**

- Increase in the percentage of individuals with developmental disabilities living in the most integrated setting.
- Increase in the number of supportive housing opportunities available in New York State.
- Decrease in the number of people residing in institutions.
- Measurable increase with satisfaction and choice of living arrangements.

## Health and Safety

### Health and Safety Reforms

Ensuring the health and safety of individuals with developmental disabilities is one of the highest priorities in all initiatives, which included progress in areas ranging from fire safety to incident reporting and investigations. OPWDD's goal is to provide supports that foster good health and confidence based on a secure, trustworthy and accountable service system. During the past year, OPWDD implemented the following improvements to enhance state and voluntary provider performance:

- Redesigned the Early Alert process, an internal review for agencies that did not meet minimum service delivery standards. OPWDD posts a list of agencies placed on Early Alert on our website with the criteria and reason for early alert status.
- Centralized the oversight of serious incidents and allegations of abuse. All provider agencies are required to report serious incidents and allegations of abuse into a statewide electronic database.
- Revised review protocols so that specific data could be obtained about the quality of services and supports being delivered by OPWDD's provider agencies.
- Shared the results of Medicaid service coordination reviews with all stakeholders on our website to further develop a provider performance report card.
- Based on a memorandum of understanding between OPWDD and the Office for Fire Prevention and Control (OFPC), OFPC recently took over the review of Life Safety Code and fire safety requirements at certain OPWDD certified residential programs.
- Surveyed thousands of state- and nonprofit provider-operated homes and identified priorities for fire safety upgrades.
- Developed a centralized mortality review system. Provider agencies are required to report all deaths, with pertinent treatment information, into a statewide electronic database.
- Created a revised local mortality review process that will be piloted in two areas of New York State.

In addition to these accomplishments, OPWDD is working on the following long-range goals for the next few years:

- Revising all review protocols to focus on the quality of individual supports and services, as well as individual health and safety.
- Developing reports and post information about agencies' performance in protecting individuals from serious incidents and abuse.
- Implementing centralized mortality reviews to improve health care and to eliminate preventable deaths.
- Publishing an annual mortality report, including actions taken to improve services based on any identified trends.
- Centralizing all certification, authorization, and review activities under the Division of Quality Improvement (DQI) to ensure consistent standards and review procedures.
- Implementing actions to grow and incentivize the Compass program to recognize and reward agencies that provide the highest quality supports and services.
- Reviewing current regulations in order to recommend changes that need to be made to better support OPWDD's values.

- Developing review procedures for care coordination.
- Re-energizing the regional advisory committees made up of self-advocates, advocates, and provider agencies to gain input from all stakeholders regarding quality initiatives.

OPWDD has an ambitious agenda to implement over the next few years and will need the support and assistance of all stakeholders. Quality improvement is not a stationary target; there will always be opportunities to improve health and safety outcomes for individuals with developmental disabilities and their family members.

### **Systemic, Therapeutic, Assessment, Respite, and Treatment Services**

OPWDD is redesigning and strengthening its system for the provision of community-based crisis prevention and intervention services to individuals with developmental disabilities and co-occurring behavioral health needs. Historically, crisis response services varied across the state and were influenced by the changing profiles of the individuals served, geographic differences, fiscal constraints, and resource shortages in the public and private sectors. The new system, based on an evidence-based program called Systemic, Therapeutic, Assessment, Respite and Treatment (START) services, will be designed to address the developmental, behavioral, and mental health needs of individuals within a comprehensive service delivery system. START will include a system for data collection and assessment of program outcomes, consultation, and clinical monitoring teams. The goals of START services are to create an infrastructure that offers crisis response and prevention services when and where they are needed, and create cross-systems linkages and care coordination between OPWDD and other state and voluntary provider agencies. Successful implementation of START services will reduce the likelihood that individuals with complex service needs will find themselves without adequate treatment options when they need them most.

During the summer of 2012, OPWDD began to work with leaders at the Center for START Services, located at the University of New Hampshire's (UNH's) Institute on Disability, to implement START services. Over the next two years OPWDD will:

- Assess available services, service gaps, and linkages/affiliations in the regions;
- Develop a strategic plan to implement START;
- Receive technical assistance and consultation from UNH to create educational trainings, collect data, and assemble clinical teams;
- Pilot START services in Region 1 and Region 3; and
- Develop the START Information Reporting System, a web-based system to collect START services data.

Implementation of a START services program typically takes four years. The present proposal to develop and implement START services runs through June 30, 2014. OPWDD intends for START services to be an integral part of the agency's mission to help individuals with developmental disabilities live richer lives. OPWDD is committed to seeing the START services initiative to the point of full implementation, and affirming the delivery of START services as a key component in the OPWDD system.

### **Goal**

People with developmental disabilities experience good health and are safe in their home and community.

**Outcomes**

- Allegations of abuse and neglect are always reported and thoroughly investigated by OPWDD and voluntary agencies in a timely manner.

**Performance Measures**

- Decrease the percent of investigations closed as inconclusive by at least 15%.
- Decrease the percentage of investigations taking more than 30 days.

## Relationships

### Positive Relationships Offer More Opportunities to Everyone

Positive Relationships Offer More Opportunities to Everyone (PROMOTE) is the OPWDD-approved staff training curriculum designed to support individuals with developmental disabilities, and to assist staff in safely and effectively addressing potential behavioral challenges. This new curriculum replaces the prior staff training program known as Strategies for Crisis Intervention and Prevention-Revised, or SCIP-R. Effective staff training is vital to helping the people we support to lead richer lives and is critical to achieving the agency mission and vision. PROMOTE is intended to reduce the likelihood of challenging behaviors by fostering positive relationships and environments.

OPWDD is strongly committed to providing staff with the skills necessary to address behavioral events through the use of positive behavior supports. In PROMOTE, these skills are called primary tools. However, when behavioral events pose an immediate health and safety risk to self or others, it may be necessary to use physical interventions, known as secondary tools, in order to interrupt truly dangerous situations. The PROMOTE program has been designed to train staff to competently respond to behavioral events, including those in which secondary tools may be necessary. Staff are taught that secondary tools are only to be used when the presenting behavior is considered to be a health and safety issue and when other less restrictive interventions are ineffective.

### Workforce Initiatives

#### Core Competencies

In 2011, OPWDD formed a direct support professional core competencies workgroup as part of the New York State Talent Development Consortium. The core competencies for direct support professionals (DSP) encompass all aspects of direct support. They are framed by seven goal areas.

The consortium has finalized the DSP core competencies, recommending that they serve as the skill standards for evaluation of direct support professionals throughout the entire developmental disabilities system.

#### NYS DSP Core Competency Goals

Putting People First

Building and Maintaining Positive Relationships

Demonstrating Professionalism

Supporting Good Health

Supporting Safety

Having a Home

Being Active and Productive in Society

Implementation is now under way in the eight nonprofit provider agencies that participate in the workgroup, and in several state offices, and will be expanding to six additional nonprofit agencies represented on the consortium's steering committee. All providers will begin using the competencies in April 2013 with the goal of full implementation by May 2014. Providers will be required to ensure that their DSP standards are consistent with the New York State core competencies. Resources, including a website containing various tools, learning resources, and strategies, regional support, and information meetings, will be made available for all providers in January 2013.

The next project for the Talent Development Consortium will be developing core competencies and providing recommended training tools for direct support professional supervisors. This effort will commence by the end of 2012.

### **Code of Ethics**

In July 2012, OPWDD announced the agency's adoption of the National Alliance for Direct Support Professionals (NADSP) Code of Ethics, based on the recommendation of the Talent Development Consortium.

Development of an implementation plan for the code began in July 2012 with an OPWDD initiative in partnership with NADSP and the College of Direct Support. Six regional DSP dialogues, or workshops, were held to engage DSPs from both the state and nonprofit providers of service.

#### **Key Elements of the NADSP Code of Ethics**

Person-Centered Supports  
Promoting Physical and Emotional Well-Being  
Integrity and Responsibility  
Confidentiality  
Justice, Fairness, Equity  
Respect  
Relationships  
Self-Determination  
Advocacy

In each of the daylong dialogues, groups of approximately 30 DSPs took part in an interactive presentation of the national code of ethics and also serve as focus groups to provide information on key issues facing the profession. That information is now serving as the guiding framework for a system-wide implementation strategy, now in development, for the code of ethics for the more than 90,000 DSPs statewide.

### **Goal**

People with developmental disabilities experience positive relationships in their lives.

### **Outcomes**

- People with developmental disabilities have meaningful relationships with friends, family, and others of their choice.
- The OPWDD and voluntary agency workforces are trained to provide positive behavioral supports to individuals with developmental disabilities.

## **Performance Measures**

- Growth in the number of individuals who experience quality relationships and access community activities.
- Increase in the number of OPWDD staff who receive PROMOTE training.
- Reduce the number of challenging behaviors by fostering positive relationships.

## **Employment and Meaningful Activities**

### **Employment First Initiatives**

OPWDD continues its efforts to greatly expand the number of people with developmental disabilities who are employed and earning at least minimum wage. Individuals with disabilities must have opportunities to work in the community with people who do not have disabilities, and earn wages that are at or above minimum wage. As of July 2012, participation in supported employment programs grew to over 9,800 people, and OPWDD's goal is to achieve continued growth through various initiatives.

OPWDD is working on multiple fronts to foster employment opportunities for individuals with developmental disabilities. This includes the following:

Developing job readiness skills for people who want to work; expanding opportunities for individuals to engage in volunteerism and other meaningful activities; building provider capacity to do quality job development and job coaching; strengthening partnerships with other state agencies; and building relationships with the business community. OPWDD is seeking to move away from day services silos to meaningful community activities. This will be accomplished by eliminating the silos within existing employment programs and blending funding streams in ways that incentivize the delivery of employment supports. The People First Waiver will not only increase opportunities for individuals to live in the community, but also expand opportunities to engage in meaningful community activities. The ultimate aim is to help individuals achieve their maximum level of independence by helping them develop the skills necessary to interact with and be actively engaged in their community. This is consistent with the goals of Olmstead: to help individuals pursue employment and meaningful day activities in the most integrated setting.

OPWDD is particularly focused on youth graduating from high school and the system changes that are needed to make employment the first and best option. In addition, individuals who participate in day habilitation, sheltered workshops, or pre-vocational services should have opportunities, if they so desire, to work in integrated community settings. Many of these individuals will be able to work part-time with other wrap around supports that provide meaningful experiences in the community.

As the service delivery system transitions to the People First Waiver, OPWDD will support the employment goals of individuals who receive services. In addition, the agency is strengthening partnerships with the Department of Labor, the State Education Department, and OMH to better leverage resources and tools toward better employment outcomes for people with developmental disabilities.

### **Community Service Initiative**

As part of the community service initiative, OPWDD will partner with its network of over 700 nonprofit provider agencies, self-advocacy groups, and parent groups across the state to increase opportunities for individuals with developmental disabilities to participate in national service programs.

OPWDD will leverage existing networks to conduct outreach and raise awareness of community service opportunities for individuals with disabilities, build capacity among voluntary agencies to engage those individuals in volunteer programs, and provide training to community-based organizations on ways to more effectively recruit, train, and place individuals with developmental disabilities in national or community service positions.

The community service project will help OPWDD utilize volunteering to educate businesses about the contributions and differences that people with developmental disabilities can make in their communities. Volunteerism can create a pathway for people with developmental disabilities to become a greater part of the New York State workforce. By connecting community service and volunteering to work and career exploration, individuals with developmental disabilities will develop the job skills and work experience needed to transition to integrated employment.

### **Monthly Community Habilitation**

OPWDD continues to work on the development of building blocks that provide greater choice and flexibility in service provision, by broadening the menu of community integrated service options for people with developmental disabilities.

One of these important building blocks is Phase 2 of community habilitation, which was implemented in November 2012. Phase 2 of community habilitation will expand this service option to individuals who reside in certified settings and have chosen to receive day habilitation and residential habilitation from the same provider. Phase 1 of community habilitation, implemented on November 1, 2010, was designed to enable more flexible service provision for individuals with developmental disabilities residing in non-certified settings. Similar to Phase 1 of community habilitation, Phase 2 enables people who live in certified settings to have greater flexibility and choice in how they spend their day and where they receive their habilitative supports. Phase 2 of community habilitation enables providers to work with individuals to design more tailored and creative approaches to habilitation services by separating the financing of supports from the site of service delivery—an important step to break down service delivery silos as OPWDD's system moves into the future.

OPWDD held two video conference training sessions across the state in September 2012 to orient providers to Phase 2 of community habilitation. The training included programmatic topics, service documentation topics, and fiscal and billing topics. Further guidance on community habilitation is available on OPWDD's website:

[www.opwdd.ny.gov/regulations\\_guidance/opwdd\\_regulations/hourly\\_community\\_habilitation](http://www.opwdd.ny.gov/regulations_guidance/opwdd_regulations/hourly_community_habilitation).

### **Faith-Based Initiative**

The first goal of the Faith-based Initiative is to assist individuals with developmental disabilities to participate as valued members in their faith community. Through consistent interaction with members of their faith community, individuals with developmental disabilities will build friendships and natural supports that provide additional opportunities to be involved in their community and practice their faith beliefs.

OPWDD's second goal is to assist individuals with developmental disabilities to extend their choices for community involvement beyond houses of worship to other areas of community integration including living in a home or an apartment of their own, access to employment,

volunteerism, as well as other activities that make up the fabric community life. This can be done by utilizing the friendships developed within the faith community to create networking opportunities in these other areas (i.e., home, work, recreation).

To meet these goals for faith-based community inclusion, OPWDD will:

- Provide statewide training (via webinars and video conferences) on spiritual indicators for Medicaid service coordinators and others charged with identifying the choices and interests of individuals with developmental disabilities;
- Address policies that hinder community involvement;
- Provide online interactive training sessions for state and voluntary agency staff to meet core competencies on awareness of individuals with developmental disabilities' spirituality;
- Examine how social network opportunities (e.g., Facebook, Google+, Twitter) may impact the ability of individuals to develop meaningful relationships within their community; and
- Train faith community leaders to assist state and voluntary agencies in breaking through some of the barriers to community involvement (i.e., transportation, opportunities).

### **Faith Community Development Grant**

In October 2012, OPWDD was awarded an 18-month community inclusion grant from the New York State Developmental Disabilities Planning Council (DDPC) to increase individuals with developmental disabilities' access and inclusion in the congregation of their faith and choice.

The Faith Community Development Grant will improve opportunities for person-centered and meaningful community participation and engagement in at least five areas of community life. Some of the goals of this grant align with the overall goals of the Faith-based Initiative program. As a grantee, OPWDD must meet specific performance metrics for the next 18 months, including:

- Engaging two nonprofit provider agencies in each of the five regional offices to participate in the grant.
- Documenting 100 people with developmental disabilities who have a goal of greater involvement in a congregation or other area of spiritual development.
- Documenting at least 50 people with developmental disabilities who as a result of project activities have greater involvement in the congregation or spiritual direction of their choice.
- Researching and developing a report on nationwide congregational inclusion strategies and techniques to promote best practices for individuals with developmental disabilities to live in their communities.
- Documenting strategies and best practices that lead to the congregational inclusion of project participants, especially those that overcome funding and policy barriers.

### **Goals**

- People with disabilities are able to work in jobs that are equal to or greater than minimum wage and/or participate in their communities through meaningful activities.

## **Outcomes**

- Employment will be the first and preferred option for all people with developmental disabilities.
- Individuals will receive employment services and have meaningful activities in the most integrated setting possible.
- Individuals will develop relationships and participate in their community through volunteer opportunities and faith-based practices of their choice.

## **Performance Measures**

- Increase in the number of individuals who are employed in integrated jobs (including those that pay minimum wage or higher).
- Increase in the number of people who are involved in their faith community or spiritual practice of choice.
- Growth in the percent of individuals who volunteer in the community.

## Conclusion

The Statewide Comprehensive Plan demonstrates OPWDD's efforts to undertake and implement system change and create well developed, person-centered services to support individuals with developmental disabilities and their families.

Our vehicle for system transformation is the People First Waiver, a 1915 b/c waiver, which combines long-term care services, behavioral health, and acute care services to holistically meet the total needs of people with developmental disabilities. OPWDD will submit waiver applications to CMS and anticipates approval by October 2013.

Over the next year, OPWDD will continue to work with all stakeholders to reform the developmental disabilities system in New York State. While many things will change, OPWDD will continue to focus on its mission and vision to provide individuals with disabilities with a choice of home, employment and meaningful activities, good health, and meaningful relationships.

## Appendix A

### Summary of 2013 County Plans

#### Introduction

The 2013 local service plan represents the fourth year of interagency collaboration among OASAS, OMH, and OPWDD. Article 41.16 of the New York State Mental Hygiene Law (MHL) requires each of the 62 counties to develop a local services plan to address the service needs of its citizens. To foster integrated collaboration, counties utilize a planning process that involves the local agency offices, individuals with disabilities, advocates, family members, service providers, and state agency representatives. Interagency collaboration improves health outcomes for individuals with co-occurring disorders who receive services from multiple state agencies.

A statewide, web-based county planning system (CPS) allows counties to identify priorities among all three disability populations and identify issues that cross traditional lines of each service system. CPS is an efficient and cost-saving application that benefits stakeholders who participate in the planning process, and provides a mechanism to analyze data and trends applicable to individuals receiving services from OASAS, OMH, and OPWDD.

#### Priority Outcomes and Strategies

Each county plan identifies priority outcomes and strategies to be achieved across all three mental hygiene agencies. A priority outcome is a broad statement of a realistic and desired goal that the county hopes to achieve over a specific period of time. This outcome statement reflects the mission, vision, and values of the individual agencies and also articulates short-term and multi-year actions to be taken. Most priority outcomes include at least one strategy to accomplish activities defined in that specific priority. A strategy is a measurable statement/objective about what needs to occur to achieve the stated outcome.

#### Outcomes for 2013

County data from the past four years reveal a significant decrease in the number of priority outcomes and a substantial increase of collaboration among the mental hygiene agencies. This year, county plans included a total of 427 priority outcomes, a 32.9% decrease from 2011. The reduction in priority outcomes was attributed to the consolidation of priorities that are common to multiple disability areas. Also contributing were limited resources and impending health system changes accompanying Medicaid redesign. Multiple agency collaboration translated to 101 separate strategies applicable to OPWDD and 193 strategies that address all three disability agencies.

Table 1 compares priority outcomes in 2010 and 2013 for all three agencies. There were 427 priority outcomes reported in 2013 versus 666 identified in 2010. This change reveals a 37% decrease in reported priority outcomes. Also, there were 167 priorities for OPWDD in 2010 and 51 priority outcomes in 2013, a 63% decrease. In 2013, OASAS and OPWDD shared only one priority outcome, whereas OMH and OPWDD shared 27 priority outcomes. Together, the three agencies shared 194 priority outcomes.

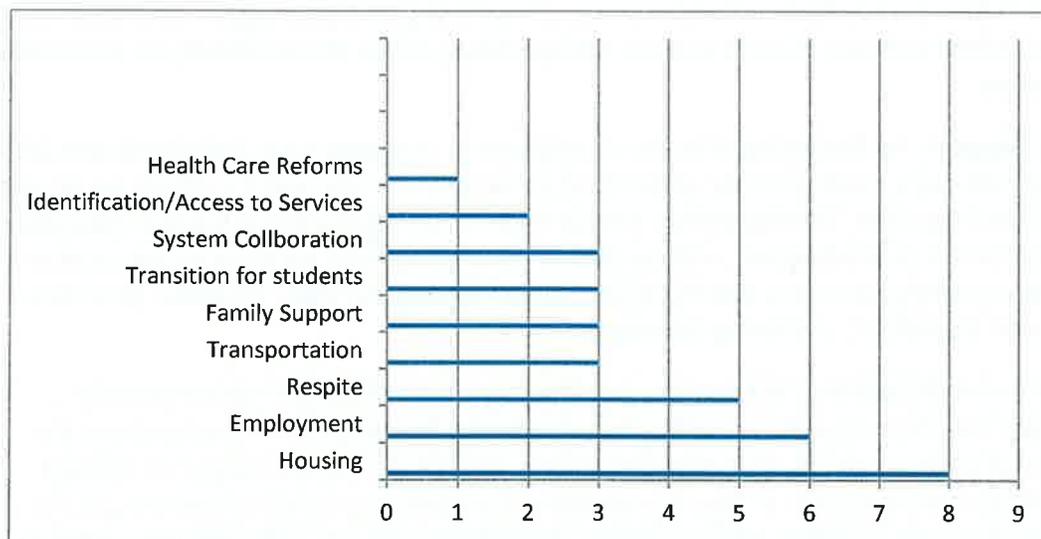
**Table 1. County Priority Outcomes by Disability Area (2010 versus 2013)**

<b>Disability Combination</b>	<b>2010</b>	<b>2013</b>	<b>Change</b>
OPWDD only	167	51	-63.45%
OASAS only	111	41	-59.31%
OMH only	116	51	-56.1%
OASAS/OMH/OPWDD	170	194	+12.1%
OMH/OPWDD	45	27	
OASAS/OMH	57	65	
OASAS/OPWDD	0	1	+100%
<b>Total</b>	<b>662</b>	<b>427</b>	<b>-36.6%</b>

A notable finding is that the total number of priority outcomes reported by the combined agencies increased by 12.1% over the past two years, whereas all other agency specific changes resulted in decreases. This trend suggests that individuals have multiple needs that require services across the three systems.

The information in Figure 1 represents themes identified from an analysis of the 51 (OPWDD only) priority outcomes and associated strategies. Of these priority outcomes, housing, employment, and respite represent the highest priority needs in 2013. The narrative in the county plans suggest that counties focused more collaboration on outcomes affecting persons with co-occurring disorders who may need services from multiple systems, or persons within each system that may need similar services (e.g., housing, employment, respite, transportation, and family support). System collaboration, access to services, and health care reform are mentioned within other themes in the narrative. Brief highlights of the top six themes are discussed below.

**Figure 1. OPWDD Agency Specific Priority Outcome Themes**



**Housing:** Safe, accessible and affordable housing is the highest priority need that affects counties in rural and urban areas. For rural settings there is a lack of adequate housing options available. In urban settings the cost of housing prevents individuals from affording fair market rent or home ownership. Several rural counties identified the need for permanent and temporary emergency housing for individuals; however, funding for housing development is an obstacle due to limited resources. Most rural counties stress the promotion of noncertified individualized housing options through programs such as ISS and CSS to accommodate part of this need. Counties suggest that more outreach needs to be done to help individuals and families understand the benefits of integrated housing options.

**Employment:** Counties discussed how low employment rates of individuals with disabilities are tied to the economy, especially in upstate New York. One of the initiatives that will help employment providers is the implementation of the New York Employment and Services System, which will help individuals with disabilities find jobs and help professionals track employment data and post job opportunities. Counties also cited the need to expand supported employment services, especially for transition age youth.

**Respite:** Family, crisis/emergency, and temporary respite is cited as a critical resource to help people live safely, remain in their homes, and provide families with relief from care giving. Similar to housing, rural counties do not have an adequate supply of respite opportunities.

Service providers reported the need to coordinate respite in their communities to best utilize this limited resource. Steps include:

1. Developing and implementing a needs assessment for respite services.
2. Developing adequate resources, based on needs assessment for respite.
3. Creating a mechanism to assure effective coordination of respite services.
4. Promoting awareness of the availability of respite services.

**Transportation:** Transportation alternatives are limited in rural counties. Medicaid transportation is available for medical appointments, but for individuals not on Medicaid or those needing special arrangements, lack of this type of transportation often hinders their ability to remain in the community. Counties cite that individuals engaged in treatment and able to access services in their county have increased sense of well-being and satisfaction. One local county provider utilizes software to communicate transportation needs and availability to all providers county-wide.

**Family Support:** As the Medicaid system transitions to managed care, individuals and family members will need training to fully understand upcoming changes and the effects on access to services and supports. Training should include information about natural support mechanisms, new approaches to assessment, and the plan of care. Successful systems transformation depends on collaboration and sharing of information among the state, counties, providers, people with disabilities, and family members.

**Transition for Students:** Counties express that many individuals with developmental disabilities lose their naturally occurring social networks following their transition from the educational system into the adult services system. Individuals require support to develop relationships and participate in their communities. Also critical to transition planning is the need to link the person's individual education plan, beginning at age 14, to the person-centered planning process to achieve greater independence and connection to community-based services and supports.

# VISIONS FOR COUNCIL'S FUTURE

STANDARD FORM NO. 64  
MAY 1962 EDITION  
GSA FPMR (41 CFR) 101-11.6

## Designing SCDD Future



The SCDD Council Leadership and Executive Management Team are currently developing a roadmap that will lead the organization in advocacy, systems change, and capacity building. We are seeking input from committee members to assist with this process by requesting input on the following for questions:

1. Please write down three recent Council accomplishments.
2. How can the Council establish itself as a model leader in California and throughout the Nation?
3. What uniqueness can the Council bring to improving the California Developmental Disabilities System?
4. How does the Council want to improve and impact the lives of people with disabilities and their family in the next 10 years?

