IDAHO COUNCIL ON DEVELOPMENTAL DISABILITIES

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C. L. "Butch" Otter
Governor

Debra Parsons
Chair

Christine Pisani
Executive Director

July 13, 2016

# M E M O R A N D U M

**TO:** Council Members

**FROM:** Christine Pisani, Executive Director

**RE:** **Materials for July 21 –22, 2016 Council Meeting**

Attached is the draft agenda and meeting packet for the summer Council meeting. The meeting will be held at the **Joe R. Williams Building, 700 W. State St., Boise.**

Welcome to our new and re-appointed Council Members: Korynne Donehey, Raul Enriquez, Holly Giglio, Emily Peterson, Jessica Rachels, Joe Raiden, Carly Saxe, and Jacque Watson. **New member orientation will take place Wednesday, July 20th from 10:00 - 4:00 in the West Conference room at the Joe R. Williams Building, 700 W. State St., Boise. Lunch will be provided.**

**Please review the packet before** the meeting. Council staff will review the packet and answer questions on our pre-Council phone call scheduled for Monday, July 18th at 10:00 am (Mountain Time) 9:00 am (Pacific Time).

On Friday, July 22nd, Sonya Rosario, Director of the Women of Color Alliance will be providing Council members and guests with an overview and understanding of cultural differences that will inform the Council's work within the 5-Year Plan. The purpose of the training is to meet five year planning requirements of being a more culturally sensitive organization. "Cultural competent/sensitive" means that the Council is committed to getting to know individuals, committed to understanding their unique life circumstances and learning as much as possible about the person's support systems both within and outside the family. **Please complete the attached homework before arriving at the Council meeting. Thank you to Council Member Jacque Watson with Maternal and Child Health for co-sponsoring this training!**

If you have questions about any of the packet materials, please call the Council office at 208-334-2178 or 1-800-544-2433.

We look forward to seeing you soon. Travel safely.

IDAHO COUNCIL ON
DEVELOPMENTAL
DISABILITIES

# Idaho Council on Developmental Disabilities
## New Member Orientation
## Wednesday, July 20, 2016

**10:00am** Introductions
Opening Remarks & Welcome

What Are Councils?

**10:30** Review Member Orientation Manual
- Law and Purpose and Mission
- Plans, Reporting, and Processes
- 2016 Work Plan Review

*~ Christine Pisani, Executive Director*

**11:45am** Lunch – Networking with members and staff

**1:00pm** Power Point Presentation: "Meet the Council"
- Member Responsibilities
- Council Officers, Committees, Work Teams
- Council Operations and Staff

*~ Christine Pisani, Executive Director*

**2:00** Policy Governance, Governmental Organization
*~ Christine Pisani, Executive Director*

Council Budget and Finance
*~ Jean Weber, Management Assistant*

Member Logistics
*~ Laurie Lowe, Office Specialist*

**3:15** "Just Give Us the Facts" Game - Team Competition

**3:45** Final Questions & Answers and Evaluation of Orientation

**4:00** Adjourn

IDAHO COUNCIL ON DEVELOPMENTAL DISABILITIES

IDAHO COUNCIL ON
DEVELOPMENTAL
DISABILITIES

# Idaho Council on Developmental Disabilities
# New Member Orientation
# July 20, 2016
# SUMMER QUARTERLY BOARD MEETING
# JRW Building, 700 W. State Street
# Boise, Idaho
# July 21-22, 2016

## AGENDA AT A GLANCE

## Wednesday, July 20, 2016

5:30-7:30 **Welcome New Council Members - Smokey Mountain Pizza**
415 East Parkcenter Blvd, Boise (optional event)

## Thursday, July 21, 2016

9:00 **Welcome, Introductions, Ground Rules, and Agenda Review**
Debra Parsons, Council Chair

9:05 **Team ICDD: Who are our Members?** Toni Brinegar, Council staff

9:45 **Announcement of Vice-Chair Election**, Debra Parsons, Council Chair

9:50 **Consent Agenda**

a. Minutes from April 2016 meeting
b. Chair Report
c. Director Report

10:00 **Financial Report,** Jean Weber, Council staff

10:10 **Approve Draft Five Year Plan and Budget**

10:45 **Break**

11:00 **2016 Idaho Partners in Policymaking Final Report,** Toni Brinegar, Council staff

11:45 **Presentation on HCBS Study Results,** Robin Greenfield, Ph.D. Associate Director CDHD

12:15 **Strategy Discussion (lunch served)**

1:15 **K.W. vs. Armstrong Class Action Update**, James Pietrowski, Attorney, Handout provided by Richard Eppink, Legal Director, ACLU Idaho

| | |
|---|---|
| 2:30 | **Break** |
| 2:45 | **Vice-Council Chair Election,** Debra Parsons, Council Chair |
| 3:00 | **Liberty Health Care**, Chris Baglio, Interim Executive Director |
| 3:45 | **Set Council Meeting Dates,** Jean Weber, Council Staff |
| 4:00 | **Administration on Community Living, Partnerships in Employment Systems Change grant opportunity,** Tracy Warren, Council staff |
| 5:00 | **Adjourn for the Day** |

## Friday, July 22, 2016

| | |
|---|---|
| 9:00 | **Welcome, Purpose of Today,** Christine Pisani, Council Director |
| 9:10 | **Being an Ally,** Representative Melissa Wintrow, District 18 |
| 9:20 | **Homework**, Christine Pisani |
| 10:00 | **Introductions to Facilitators and Participants**, Sonya Rosario, Executive Director, Idaho Women of Color Alliance and Representative Melissa Wintrow |
| 10:15 | **Is the ICDD Mission Statement Representative of the Council** |
| 10:30 | **Break** |
| 10:45 | **Sticks and Bones "BUT" Words will Never Hurt Me** |
| 11:15 | **Small Group Work (lunch served at 12:15)** |
| 1:00 | **The Invisible Knapsack** |
| 2:00 | **The "S" (squaw) Word (Movie)** |
| 3:00 | **Questions and Discussion** |
| 4:00 | **Council Meeting Evaluation**, Alan Aamodt, Council Member |
| 4:30 | **Adjourn** |

## Next Meeting: **October 27-28, 2016**

***Items in green require a vote.**

*The mission of the Idaho Council on Developmental Disabilities is to promote the capacity of people with developmental disabilities and their families to determine, access, and direct the services or supports they need to live the lives they choose, and to build the communities' ability to support their choices.*

# Election of Vice-Chair

## Background Information:

At the summer meeting, Council members select a person to serve as the Council Vice-Chair for one year. As with the Chair position, this position is limited to Council members who are self-advocates, parents, or guardians.

**Vice-Chair:** Performs all duties of the Chair in the Chair's absence and may be assigned other responsibilities by the Chair or the Council.

## Recommended Action:

If you are interested in serving as either Vice-Chair be prepared to nominate yourself or have someone nominate you. If you know of someone on the Council that you think would be good in this position, you can nominate them, but be sure to ask their permission first. The election will be announced on Thursday morning and held on Thursday afternoon.

## Recommended Action:

Listen to those nominated, ask questions if you have them, and vote.

## Notes:

IDAHO COUNCIL ON DEVELOPMENTAL DISABILITIES

# Idaho Council on Developmental Disabilities
# VICE CHAIR NOMINATION FORM

The Vice-Chair position is limited to Council members who are self-advocates, parents, or guardians.

Vice-Chair: Performs all duties of the Chair in the Chair's absence and may be assigned other responsibilities by the Chair or the Council.

If you are interested in serving as either Vice-Chair be prepared to nominate yourself or have someone nominate you. If you know of someone on the Council that you think would be good in this position, you can nominate them, but be sure to ask their permission first.

**Council Member Name:** _____

**Nominated by:** _____

**Years of Service on the Council:** _____

**Offices held on the Council:** _____

**Outside Involvement:** _____

_____

**Other Activities:** _____

_____

**Reason for Seeking Office:** _____

_____

**Why do you think you would be a good Vice-Chair?** _____

_____

_____

# Consent Agenda

## Background Information:

The Consent Agenda contains items that require a vote by the Members. If there are items on the Consent Agenda a Member wishes to discuss before that vote a Member may make a motion to move the item to the Business Agenda.

## Recommended Action:

Review and approve the Consent Agenda.

## Notes:

# IDAHO COUNCIL ON DEVELOPMENTAL DISABILITIES
# SPRING QUARTERLY BOARD MEETING

## Wednesday, April 27, 2016

**Members Present:**

Alan Amodt
Jim Baugh
Rebekah Forster-Casey
Dave Dekker
Debra Parsons
TeRonda Robinson
Colleen Sisk
Jacob Head
Kelby Selders
Denise Wetzel
Jim Baugh
Robin Greenfield for Julie Fodor
Charlie Silva
James Steed
Raul Enriquez
Ian Bott

**Members Absent:**

Stephanie Perry
Joe Raiden
Julie Fodor
Jenn Halliday
Jacque Watson

**Staff Present:**

Christine Pisani, Toni Brinegar, Tracy Warren, Jean Weber, Laurie Lowe, Suzie Hanks

**Guest:**

Cortland Rammel

**Council Meeting:** Conference Room, Springhill Suites. Meeting was called to order at 9:00 am by Debra Parsons, Council Chair.

**Announcement:** Election of Council Chair. Nominations need to be to Tracy Warren by noon today.

**Consent Agenda:** The Consent Agenda, consisting of the January 2016 Draft Minutes, the Chair Report, the Executive Director Report, and Conference Funding applications were sent to the Members on April 15, 2016 for review.
**Move to Approve: Dave Dekker, TeRonda Robinson seconded, Motion carried.**

**Financial Report:** Jean Weber, Council staff presented the financial report. **Move to approve: James Steed. Dave Dekker seconded. Motion carried.**

**Member Recruitment:** There are currently three vacancies for persons with a Developmental Disability, and four vacancies for the parent of a child with a Developmental Disability. A membership committee was formed and interviews have been completed. Recommendations have been made to the Governor.

**Staffing Proposal:** The Executive Director met with the State Legislative Budget Analyst to develop a plan to add one staff member to facilitate gathering and analysis of required data. Requesting permission from the council to make the request to the state for additional funding to cover 90% of this position, and if funding is approved, add this position to the staff. **Move to authorize this effort: James Steed. TeRonda Robinson seconded. Motion Carried.**

**Activity:** Council members participated in an exercise to identify the roles that they typically take on when working in groups. How to best utilize this knowledge was discussed.

**Quarterly Progress Report:** Staff reviewed highlights of progress on objectives for the 2nd quarter of FY 2016.

**Legislative Report:** Staff presented information on legislative priorities of the council and additional issues the Council was involved in for this legislative session. Jim Baugh provided clarification on some of the issues.

**Closed Executive Session: Move to approve: Denise Wetzel moved to take Council into Executive Session to discuss the performance of the Executive Director. Rebekah Forster-Casey seconded. Motion carried. 12:17pm.** Executive Director and staff left the meeting room.

**Executive session:** Council Meeting returned to open session at 12:55 pm. **Move to approve: James Steed moved to approve 3% CEC raise for Executive Director Christine Pisani. Ian Bott 2nd. Motion Carried.**

**Public Input Report:** The Council conducted a 5 year strategic plan survey online via Survey Monkey. Staff also gathered input from a variety of stakeholders. Results were presented and discussed.

**Council Chair Election:** Nominees for the post of Council Chair are: Debra Parsons and Joe Raiden **Election Results:** Majority **voted for Debra Parsons.**

**Preparation for Five Year Plan:** Staff recapped what the council has accomplished during the past five years. Looked at the strengths that the council has developed and where the council has been most effective. Discussion followed regarding specific outcomes and difficulties. Council members were encouraged to think about their abilities and how they can be used in accomplishing goals.

**5:02 pm Recess until tomorrow.**

## Thursday, April 28, 2016

**Members Present:**

Alan Aamodt
Jim Baugh
Rebekah Forster-Casey
Dave Dekker
Stephanie Perry
Debra Parsons
TeRonda Robinson
Colleen Sisk
Jacob Head
Kelby Selders
Denise Wetzel
Jim Baugh
Robin Greenfield for Julie Fodor
Charlie Silva
James Steed
Raul Enriquez
Jacque Watson
Jenn Halladay (left at 4:00 pm)
Ian Bott

**Members Absent:**

Joe Raiden
Julie Fodor

**Staff Present:**

Christine Pisani, Toni Brinegar, Tracy Warren, Jean Weber, Laurie Lowe, Suzie Hanks

**Guest:**

Cortland Rammel

**Meeting was called to order at 9:02am.**

**Team Building:** Rebekah Forster-Casey led the council in a team-building exercise to foster conversations about different expectations, assumptions and opportunities throughout the disability community, and how those can be utilized or overcome.

**Five Year Planning Activities:** Christine Pisani discussed what was going to be happening for the remainder of the day in the format of the presentations, and the reasoning behind the selection process.

Presentations were made by council staff on the potential goals of Employment, HCBS Services, Abuse-Neglect, Secondary Transition, Education, and Caregivers.

Council decided to focus on HCBS Services and Secondary Transition as the primary goals for next Five Year Plan.

Council staff explained how the priorities determined by the Council must work into the DD Act. The goals set within the priorities have to be measurable against the DD Act. Objectives to be achieved along the way are the things that will be set in annual plan. A work-plan will be drafted in the next few weeks, which will be sent to council members, and a conference call will be set up to discuss the work-plan. There will be some new council members in July when the next council meeting takes place, which is where the plan will be voted on and adopted.

**3:30 pm. Recess until tomorrow.**

## Friday, April 29, 2016

**Members Present:**

Alan Aamodt
Rebekah Forster-Casey
Dave Dekker
Debra Parsons
TeRonda Robinson
Colleen Sisk
Jacob Head
Kelby Selders
Denise Wetzel
Richelle Tierney for Julie Fodor
James Steed
Jacque Watson (left at 1:00 pm)
Ian Bott
(Arrived at 10:00 am)

**Members Absent:**

Jim Baugh
Raul Enriquez
Julie Fodor
Jenn Halladay
Stephanie Perry
Joe Raiden
Charlie Silva

Meeting was called to order at 9:00 am.

**Review of Work from Yesterday:** Confirmed that the Council is satisfied to name the two five-year goals as Quality in HCBS Services and Secondary Transition.
Ideas about goals for the Five Year Plan

- HCBS future state
- Medicaid expansion, access to all Idahoans
- Planning meetings led by the Self Advocate
- New provider "Person Centered Planning Specialist"
- Providers have rate increase to hire good staff with salary for retention
- More money for assisting institutionalized for community based living
- Improved self-determination, rules implemented with proof that it made a difference.
- Improved tool to gather data, better data management system
- Ability based planning, families understand how PCP works, understand strength based planning. Family mind-shift.
- Peer services, mentoring from experienced parents to help see the opportunities, give hope.

- Give parents positive messages from professionals.
- Create sense of community and encouragement.
- Address dual-diagnosis. Training, funding. Improved competency in services.
- Cooperation between mental health and developmental disability, not silos.
- Address provider shortage.
- Talk to Med School startup to try to change the mindset. Encourage medical professionals to emphasize what can do, not what can't do.
- More parents and adults influencing the outcomes.
- Private insurers picking up early intervention instead of always relying on Medicaid.
- Data driven decisions rather than ideology and money.
- Empower families through education and information.
- Collaborate with other states to learn strategies that work. Washington State "Community Protection Waiver".
- Adequate funding/staffing at DHW to support system.
- Stakeholders at the table.
- Idaho Parents Unlimited on board with PCP.
- An informed network of adults and parents are educating and working with DHW and other agencies understanding how to deliver message in a way agencies understand and operate.
- Support language and culture differences.
- Rally the people who have been on the council or in Partners to develop community connectors.
- Transition
- In freshman year have a plan all laid out that will carry through all areas.
- School-teachers are trained in what different needs might be.
- Full inclusion all the time.
- Increased employment rate.
- More self advocates mentoring each other, all the way through post secondary education.
- Supported decision making, not just take over guardianship.
- Make sure the schools know what PCP is so it can be integrated and carry through.
- Empowered in medical care

- Way for youth to learn more about self advocacy early. They don't get it until they're adults.
- Meaningful job/work experience by the time they're adults.
- Families need to know what resources are available early in the process.
- Transportation options.
- All High School freshmen, not just dd.
- More meaningful jobs, not just make work jobs. Need access to jobs they can be passionate about.
- Teachers have to embrace belief that students can achieve and excel. Help students identify the opportunities.

**Steps we need to take?**

- Partnering with self advocacy group for youth. Very successful I TV. IFFCMH
- Play to our strengths. Community transition teams, connect resources together.
- Taking responsibility as self advocates. Empower parents and educators to let us fail. Learn how to take responsibilities for own actions. Families have tendency to shelter children.
- Provide age-appropriate role models. Build better connections to younger self-advocates. Develop network of self advocates who could go around to speak at schools and say "See what you can do."
- YLF age 16-22. Actively recruit members to the Council in that age range.
- Think about developing a network of SA who are trained in PCP who can travel to schools and facilitate with youth.

**What do we see**? What are some of the themes that have come out of our discussions?

- **Education for families**
- **Empowerment for families at a young age**
- Supported decision making
- Targeting young self advocates
- Empowerment of youth in **person centered planning process** – encourage participation of younger PCP advocates.
- Education for teachers.
- Improving employment outcomes

- Setting higher expectations for all youth – tools for peers (education, training, resources)
- Education in supported decision making.
- All youth need an inclusive asset based community. Educating youth as a whole. Empowering youth.
- HCBS
- Medicaid Expansion
- Participant reported QA of HCBS
- Education on HCBS – public
- Insurance Reimbursement
- Reconnect former ICDD, self advocates, and PIP members
- Connect with culturally diverse population – expand community connectors
- Strengthen existing relationships with existing partners and leaders in the state
- Provider Requirements/Training
- Access to service providers
- Education and awareness for future medical professionals
- QA of HCBS including families in a quality PCP and children's service.
- Breaking down silos – collaboration between DD and MH – dual diagnosis

**Recognition of Outstanding Member:** Denise Wetzel is leaving the council. A certificate of appreciation was presented.

**Next meeting July 21-22. New Member Orientation on July 20.**

**Jacob Head moved to adjourn. Ian Bott seconded. Motion Carried. Meeting adjourned at 3:00 pm**

## Idaho Council on Developmental Disabilities

## Council Chair Report

### Summary of Council Chair Activity

### April-June
### July 21, 2016

This quarter has been busy indeed. I have been researching issues that affect vulnerable populations in Idaho. I was invited to a meeting in my county to address concerns about emergency plans for those with developmental disabilities and the elderly in our very rural state. It is clear that Idaho has work to do in gathering information about services in order to support vulnerable populations to have a clear plan for emergency situations.

## Idaho Council on Developmental Disabilities

# Council Executive Director Report

## Summary of Council Director Activity
## April through June
## July 21, 2016

- **April 4-8, 2016**
  DD Council Meeting Prep
  Person Centered Planning meeting for individual
  Attend CID Board Meeting
  Attend monthly CID meeting
  K.W. vs. Armstrong – ACLU Phone Meeting
  Attend 7th Session of Partners in Policymaking
- **April 11-15, 2016**
  DD Council Meeting Prep
  Person Centered Planning meeting for individual
  Council member phone calls for 5 year planning
  Membership Committee meeting
  Self-Direction Quality Assurance meeting
  Draft 2016 Legislative Report
  Waiver Amendment Public Comments
  Pre-Council staff meeting
  Council Membership Review
- **April 18-22, 2016**
  DD Council Meeting Prep
  Third Quarter Budget Review
  Staff Performance Evaluations
  SWITC Community Stakeholder meeting
  SWITC Project Workgroup Meeting
  National Core Indicator Family Survey Work
  Waiver Amendment Public Comments
  Partners Planning Meeting
  Call with 2016 Partner
  Council Membership Review

- **April 25-29, 2016**
  DD Council Meeting Prep
  K.W. vs. Armstrong – ACLU Meeting
  Pre-Council staff meeting
  Community Care Advisory Council meeting
  NACCD Webinar
  Council Membership Review
  Spring Quarterly Five-Year Planning Council meeting
- **May 2-6, 2016**
  Meet with Andy Imparato, Executive Director AUCD
  Staff Five-Year Planning Meeting
  Staff Performance Evaluations
  Meet with Gary Sandusky Post DD Council planning meeting
  Prepare materials for Partners Graduation
- **May 9-13, 2016**
  No Wrong Door Governance Committee
  Collaborative Workgroup Steering Committee Meeting Prep
  CWG Steering Committee meeting
  Meeting with Tammy Perkins, Governor's office
  Attend 8th Session of Partners in Policymaking
- **May 16-20, 2016**
  NACCD Self-Advocacy call
  Call with Oregon DD Council RE: Partners in policymaking perspective
  SWITC workgroup meeting
  ABLE Act stakeholder committee
  Meeting with VR Counselor office assessment for transition age student in fall
  Staff review of five-year plan meeting
  AIDD Phone call
  Public comment on Residential Habilitation Rules
- **May 23-27, 2016**
  CWG meeting prep
  Collaborative Workgroup meeting
  No Wrong Door Person Centered Counseling Workgroup
  Council phone call
  Draft ABLE stakeholder white paper
  Website Updates
- **May 30-June 3, 2016**

Attend CID monthly meeting
Meeting with Sara Stover to discuss Research Analyst position
Rally in support of student in Diedrich
Draft ABLE stakeholder white paper
Staff Performance Evaluations
NCI Meeting
Website Updates

- **June 6-10 , 2016**
  Meeting with Senator Martin and Rep. Wintrow Medicaid transportation contract
  Draft ABLE stakeholder white paper
  CID Board Meeting
  Council Chair call
  Council meeting prep
  No Wrong Door Governance meeting
- **June 13-17, 2016**
  Meeting with Sara Stover PIE Grant application
  Staff meeting to plan five year strategies
  Meet with Gary Sandusky for five year plan
  Council meeting prep
  Website updates
- **June 20-24, 2016**
  NACCD National Call
  Medicaid Integrity Unit training
  Meeting with Sara Stover
  Council meeting prep
- **June 27-June 30**
  Vacation

# Financial Report Third Quarter – Federal Fiscal Year 2016

## Background Information:

A financial statement reflecting our fund balance and the amount spent to date in this Fiscal Year will be presented at the Council meeting. The Council operates on a federal Fiscal Year (Oct. 1- Sept. 30). The Council is responsible for overseeing and approving the budget.

## Recommended Action:

Review and approve the financial report that will be distributed at the meeting.

## Notes:

# Draft of 2017-2021 Five-Year Plan & Budget

## Background Information:

Every five years the Council undertakes the research, public input, and drafting of a Five-Year Strategic Plan, as required by the Administration on Intellectual and Developmental Disabilities. The Five-Year Plan serves to direct the priorities of the Council beginning October 1, 2016 through September 30, 2021. Along with the Five-Year Plan, a budget, based on the Council's 2017 federal and state fiscal year appropriations, is developed to implement the plan.

Members will hear a report from staff that includes all of the public input received. Members will then review the draft of Five-Year Plan and the proposed 2017 Budget. After full review, members will be asked to vote to accept the plan and budget as presented or propose changes.

## Recommended Action:

Review the final draft Five-Year Plan and proposed budget and vote to approve as presented or propose changes.

## Notes:

# K.W. vs. Armstrong Class Action Lawsuit Update

## Background Information:

This lawsuit is about the Idaho Medicaid program for adults with developmental disabilities. It is a class action. That means that every participant in the Home and Community Based Services Adult Developmental Disability program is part of the lawsuit. Every person who applies for the program is part of the lawsuit too. The lawsuit is called K.W. v. Armstrong in court.

The lawsuit filed by the Idaho American Civil Liberties Union (ACLU) asked the Idaho Department of Health and Welfare (IDHW) to fix a number of problems within the program. The notices the IDHW sends about individual budgets needed to be fixed. The assessment and budget system at the Idaho Center for Disabilities Evaluation (ICDE) needed to be fixed. And the appeal and hearing officer system needed to be fixed.

The court made its decision at the end of March 2016. The decision gave the IDHW 90 days to propose four specific plans to fix the issues in the program:

(1) A plan to fix the budget tool and test it regularly

(2) A plan to make sure every participant has somebody to help them appeal their budget amount or ask for a higher budget

(3) A plan to specify what you need to show to increase your budget

(4) A plan to let you prove whether your SIB-R scores are correct

On July 13, 2016 the IDHW submitted their specific plans to address the identified issues in the lawsuit.

## Recommended Action:

Review Idaho ACLU handout that will be provided at the Council meeting, ask questions, inform others in your communities.

## Notes:

# Idaho Partners in Policymaking Final Report

## Background Information:

The Idaho Partners in Policymaking 2015/2016 class graduated on May 14, 2016. There were 14 self-advocates and 11 parents who completed the intensive leadership development training this year. With a southern Idaho focus, Partners came from as far as Idaho Falls to Canyon County in Caldwell. This class was a class of "firsts" for the Idaho: the first time a child of a Partners grad participated in Partners; the first participant with a diagnosis of Spina Bifida; the first Spanish-speaking parent participant; the first time that self-advocates outnumbered parents. We look forward to continuing to develop relationships with this class of Partners in the coming years.

## Recommended Action:

Listen and ask questions

## Notes:

# Home and Community Based Statewide Study

## Background Information:

The *Centers for Medicaid and Medicare Services (CMS) released a new set of Home and Community Based Rules that became effective on March 17, 2014 made this new rule. The Rules were presented to and approved by the Idaho Legislature this past session. The ICDD was in support of the new rules. These rules take effect July 1, 2016. The new rules define and describe home and community based settings under section 1915 (c) waivers and section 1915 (i) state plans. The rules also sets forth requirements for a person-centered planning process and person-centered service plans. The rules emphasize integration and supporting access to the greater community.

The Center on Disabilities and Human Developmental at the University of Idaho, the DD Council, and the Idaho Department of Health & Welfare collaborated on a statewide face to face study of adults participating in the adult Developmental Disabilities Medicaid program, a Home and Community Based Service. This study, "Choice and Community: Seeking the Voice of Adults with Developmental Disabilities" was conducted from August 2015 – April 2016. After three years, a follow up study will be conducted to see if there are changes in the perceptions of the same respondents.

The purpose of the study was to identify the perceptions of adults with developmental disabilities who were receiving Home and Community Based Services (HCBS) (Medicaid Program: State Plan Home and Community-Based Services, 2014) or their guardians regarding the extent to which individuals were integrated into the community, had choices, individual rights, and autonomy within a living setting. The study was designed to provide the Idaho Department of Health and Welfare with information from individuals or their appointed guardians about aspects of the new rules that are currently being implemented and what aspects of the rules are not being implemented.

## Recommended Action:

Listen, learn, and ask any questions you may have.

## Notes:

*CMS is the Federal agency that oversees Medicaid in all states.

# Choice and Community: Seeking the Voice of Adults with Developmental Disabilities

CENTER ON DISABILITIES AND HUMAN DEVELOPMENT
IDAHO COUNCIL ON DEVELOPMENTAL DISABILITIES

May 2016

This study, "Choice and Community: Seeking the Voice of Adults with Developmental Disabilities" was conducted by the Center on Disabilities and Human Development at the University of Idaho and the Idaho Council on Developmental Disabilities in collaboration with the Idaho Department of Health and Welfare from August 2015 - April 2016. After three years, a follow up study will be conducted to see if there are changes in the perceptions of the same respondents.

## Purpose of Study

The purpose of the study was to identify the perceptions of adults with developmental disabilities who were receiving Home and Community Based Services (HCBS) (Medicaid Program: State Plan Home and Community-Based Services, 2014) or their guardians regarding the extent to which individuals were integrated into the community, had choices, individual rights, and autonomy within a living setting. The study was designed to provide the Idaho Department of Health and Welfare with information from individuals or their appointed guardians about aspects of the new rules that are currently being implemented and what aspects of the rules are not being implemented.

The study addressed the following four research questions:

1. *How do responses vary among individuals residing in certified family homes and supported living settings?*
2. *How do responses vary among individuals in different regions and geographic designations?*
3. *How do responses vary among individuals who need various levels of support as designated by the Scales of Independent Behavior-Revised (SIB-R)?* (Bruininks, Woodcock, Weatherman, & Hill, 1996)
4. *What are the perceptions of adults with developmental disabilities and/or their guardians who receive Medicaid Home and Community Based Services, regarding the extent to which they are integrated into the community, have employment opportunities, and choices within their living situations?*

The following sections describe the design of the study including a description of the respondents, interview protocol, and procedures.

## Design of Study

Respondents

A random sample of 831 individuals drawn from a list of 3200 adults who receive HCBS were included as possible participants. The sample was drawn from all seven regions of the state. The list of 831 randomly identified names was provided to the Idaho Council on Developmental Disabilities by the Idaho Department of Health and Welfare in August 2014. A total of 112 adult recipients or their guardians agreed to participate. Adult recipients who participated in the study ranged in age from 18 to 68. Sixty-three percent of the adult recipients were male and 37% were female. Forty-seven percent of the

recipients lived in a certified family home, 42% lived in a supported living setting, and 11% lived in what was defined as “other.” The “other” category was a person who was directing his or her own services utilizing the “My Voice, My Choice” (self-direction) program. Eighty-five percent of participants lived in an urban setting, 8% lived in a rural setting, and 7% lived in a frontier setting, as defined by the Idaho Department of Health and Welfare (Appendix A).

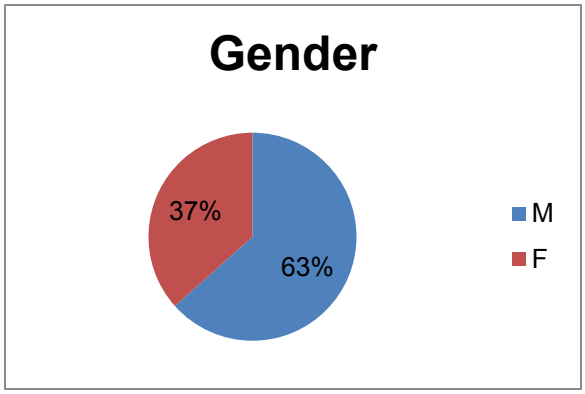



Figure 1

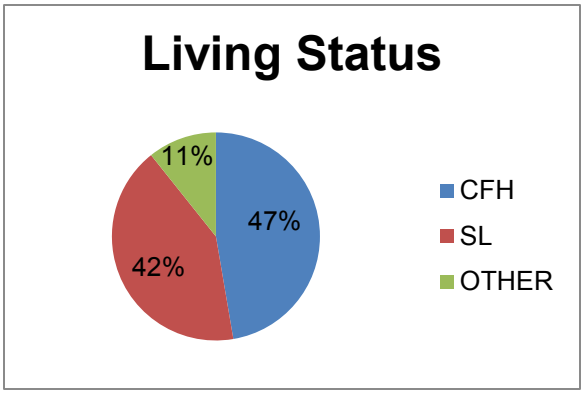



Figure 2

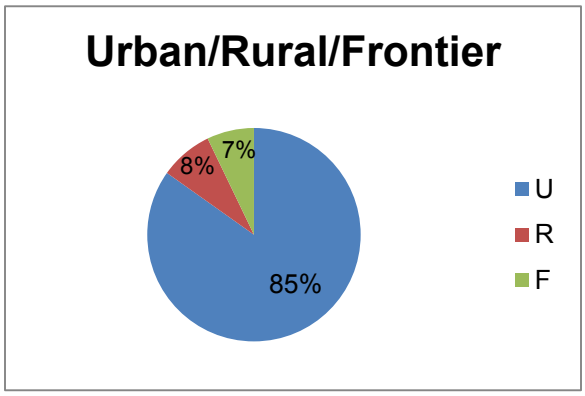



Figure 3

Procedure

Prior to conducting the study, a letter and two consent forms were sent to all the adult recipients on the sample list or their guardians. The study began in region one in September 2015 and ended in region seven in March 2016. One form required the adult recipient or the legal guardian to give his/her consent to participate in the study and the second form required a signature to release the recipient’s SIB-R score to the researchers. The signed SIB-R consent forms were sent to the Department of Health and Welfare on a monthly basis and a list of scores was then returned to the University of Idaho.

Following each regional mailing, a phone call was placed to an adult recipient or a legal guardian to confirm receipt of the letter and the consent forms. The recipient or guardian was asked if they would be willing to participate in the study. People who expressed an interest in participating were encouraged to mail in the consent forms. Once the consent forms were received with an authorized signature, the researchers made a second call

to arrange a date, time, and location for an interview. Interviews took place in a recipient or guardian's home, developmental disability agency, or a community setting such as a restaurant or library. Each interview was tape recorded and transcribed for analysis.

### Interview Protocol

The interview protocol (Appendix B) was comprised of 20 core questions in categories that were aligned with components of the five standards that all Home and Community-Based Services are required to meet according to federal regulations. These include: a) integration into the community; b) individual choice; c) individual rights; d) autonomy; and; e) choice regarding services and providers. Questions were also aligned with the Department of Health and Welfare's "Person Centered Planning Process and Plan Requirements" (Appendix C).

In August 2015, a pilot study was conducted with three adult recipients who had various SIB-R scores. Following the pilot, revisions were made to the language of the protocol. Revisions were also made to the protocol following interviews in regions one and two. These revisions included modifying the order of the questions and adding clarifying questions or language to meet the needs and experiences of the respondents. For example, participants confused the terms "roommate" with "housemate." A question was added to the protocol to distinguish between someone who shared a room with the recipient versus some who lived in the home.

### Training for Researchers

The interviews were conducted by three researchers from the Center on Disabilities and Human Development at the University of Idaho and one researcher from the Idaho Council on Developmental Disabilities. An initial two-hour training was conducted with the researchers in August 2015. The training included a review of the purpose of the study and initial guidelines for conducting an interview with an adult recipient and/or their guardian. Guidelines included topics such as ways to avoid research bias, pacing of questions, phrasing and rewording of questions, dealing with abstract concepts such as "time," avoiding induced acquiescence, and avoiding response bias. Reliability on the protocol was established with researchers through the initial training and through ongoing regularly scheduled follow up discussions**.**

### Data Analysis

Each interview was transcribed from the audio recording and given a code to identify the region, the date, and initials of the adult recipient. Interviews were then reviewed by the researchers and entered into a data processing software. Totals and percentages were calculated for quantifiable questions (e.g. yes/no) and qualitative data (e.g. individual support plan data) was entered into a word processing program.

Researcher comments were also included as part of the data collection process. Additional comments made but the adult recipient or their guardian were noted in the areas of employment and individual support plans. These comments were then reviewed for themes within a region and statewide.

Respondents

A total of 112 out of 831 adult recipients of HCBS, their guardians or support personnel participated in the interviews.

The adult recipients from the sample fell within all of the SIB-R levels of support with the exception of the “infrequent” level. As such, there were a range of ways that people responded or were able to respond to the interview questions. To provide a clear description of who was answering the questions a coding system was developed to indicate how much of an interview was answered by the adult receiving HCBS and how much had been answered by a guardian or support person. At the conclusion of an interview, the researcher rated the active participation of the focus individual. The interview was rated as a “1” if 90% or more of the interview questions were answered solely by the person receiving HCBS. The interview was rated as a “2” if a guardian or support person assisted the individual with a majority of the questions, and the interview was rated a “3” if the guardian or support person answered 90% or more of the interview questions.

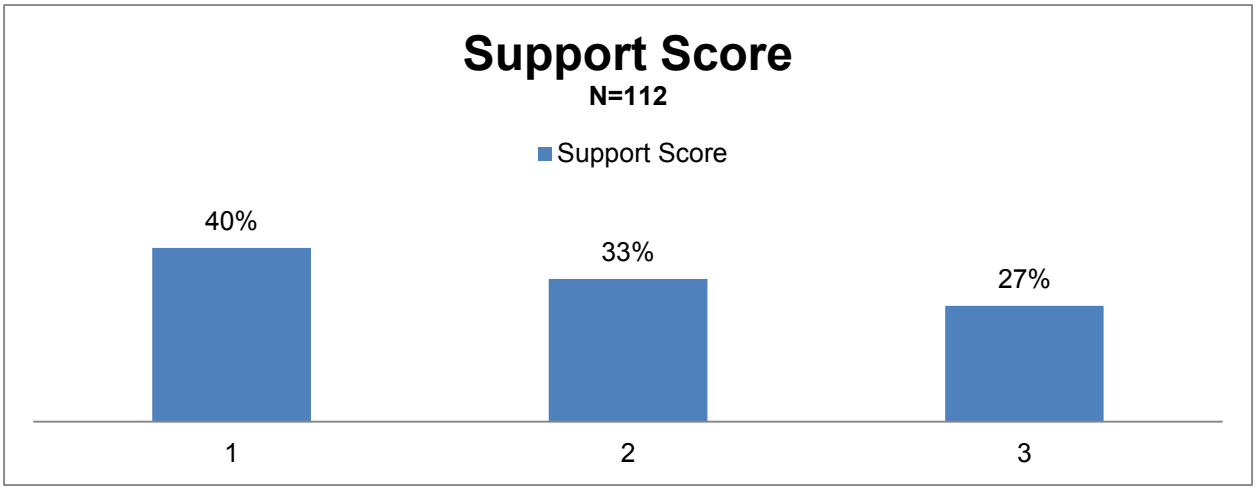



Figure 4

Role of a Support Person

A support person actively participated in 60% of the interviews. A support person was defined as either a legal guardian or designated staff in a living situation who had permission from the guardian to participate in the interview. These people played several roles depending upon the active participation of the focus individual. They might clarify information or expand on an answer. They might reframe a question to help an individual understand the question, or they might explain an answer given by the individual. If a support person answered some or all of the questions for the adult recipient, the researcher verified the answers by asking the respondent such questions as “Why do you say that?” or “Can you give me an example?”

## Results

The following section details the results of the study for each of the four research questions. As stated above, the categories and questions on the interview protocol were aligned with major components of the rule. These categories included living situation; individual choice; employment; integration into the community; and personalized plan.

1. *How do responses vary among individuals residing in certified family homes and supported living settings?*

The study involved 53 people who lived in a certified family home and 47 who lived in a support living setting. A third setting labeled as “other” was added to the data analysis during the interview process. The “other” category included individuals who were on self-direction and lived with a parent, family members, or by themselves. There were 12 adult recipients in this category.

The study did not find any meaningful differences in responses to the interview questions given for the living, individual choice, employment, integration into the community, or personalized plan category.

2. *How do responses vary among individuals in different regions and geographic designations?*

Of the 112 people who participated in the study, there were no meaningful differences in responses among adult recipients living in the seven regions other than some access to community activities due to rural/frontier settings.

3. *How do responses vary among individuals who need various levels of support as designated by the Scales of Independent Behavior-Revised (SIB-R)?*

The goal of the study was to interview individuals who were receiving HCBS or their guardians as to their perceptions of their current services. The interview process included individuals at support levels as listed on the SIB-R.

Scores on the SIB-R are categorized into six levels of support. Levels include “infrequent/no support,” “intermittent,” “limited,” “frequent,” “extensive,” and “pervasive.” Adult recipients in the study fell within five of the levels. Those receiving “infrequent/no support” were not included in the study. Additionally, individuals deemed “dangerous to self or others” by the Idaho Department of Health and Welfare were excluded from the sample. As noted above, support levels for adults receiving services were provided to the researchers from the IDHW on a monthly basis once a signed release form had been sent to the researchers.

One of the early findings of the study was that the SIB-R scores did not always correspond with an individual’s ability to be a participant in an interview. For example, there were people who were categorized as “limited” on the SIB-R but were unable to actively participate in an interview, where other people were categorized as “extensive” due to physical needs and were able to fully participate in the interview process. As a result, it was difficult to determine if and how responses varied across support levels.

4. *What are the perceptions of adults with developmental disabilities and/or their guardians who receive Medicaid Home and Community Based Services regarding the extent to which they are integrated into the community, have employment opportunities, and choice within their living situations?*

**Category A: Living Situation**

1. Do you have a room of your own?

   The results of the study indicated that 96% of adults receiving HCBS had his or her own room. The remaining 4% of individuals shared a room with their spouse or a parent.

2. Do you have a housemate?

   Results for this question indicated that 81% of adult recipients had a housemate(s) and 19% lived alone.

3. Did you choose your roommate/housemate?

   This question was asked of people who were in a "supported living" setting. Of those people asked, 42% of adult recipients indicated that they did not choose their roommate or housemates. Typical reasons for not choosing a roommate or housemate included "the agency chose the home and housemate already lived here," "limited availability of vacancies," or "my family choose for me."

4. Can you be by yourself if you want to?

   Responses by individuals receiving services, their guardians or support personnel indicated that 87% of people were able to be alone. The question was oftentimes clarified to define "alone" as being able to go to another room and "be by themselves" without anyone in the room. Guardians or support personnel were quick to point out that a person might be able to go to another room in the home but could not be left alone in the house. The remaining 13% of adult recipients were not allowed to be alone in the house due to safety concerns. For example, one respondent said, "He can't do anything alone. He doesn't understand concepts so if you leave him alone he could just run out into the street and get hit by a car," or, for health reasons such as the individual had a serious seizure disorder.

5. If you are in your bedroom do people knock before coming in?

   The results for this question indicated that people knocked or said something verbally before entering the room of 83% of the adult recipients. Results showed that people did not knock or indicate their presence verbally for 17% of individuals. Reasons given for not knocking included "I like the door always open," or "we are family so it doesn't matter," "health and safety concerns," and "he is not concerned with privacy."

6. Do you get the privacy you want when you get dressed and use the bathroom?

   Regarding privacy issues, 88% of respondents indicated that the adult recipients have privacy when dressing or using the bathroom and shower. The other 12% of adult recipients were regarded as needing "full assistance" when dressing, showering or using the bathroom and were not physically able to participate in those activities by themselves for safety reasons.

**Category B: Individual Choice**

7. Are you able to see people that are important to you whenever you want to?

   Results of the study indicated that 89% of adult recipients were able to see people that were important to them. The remaining 11% indicated that they were not always able to see people that were important to them due to distance issues, mileage constraints of support personnel or the lack of "flex staff." In some instances, the adult recipients all had to travel together rather than taking individual trips to visit a particular person.

8. Do you get to eat when you want?

   Respondents to this question indicated that 91% of the adult recipients could eat when they wanted to. People were able to get a "snack" at any time. However, this did not mean that they were able to get a main meal when they wanted to for reasons such as an individual "ate with the family" or the home had "set meal times." The remaining 9% could not eat when they wanted to due to health issues such weight gain, diabetes, or aspiration concerns. Seventy-five percent of those individuals had the restriction noted on their plan.

9. Do you choose what you eat?

   Regarding food choices, 80% of respondents indicated that the adult recipients could choose what they ate during the day. The remaining 20% were said to have had restrictions for reasons that included "gaining weight," "eating too much sugar," "diabetes," or consuming too much of one item like a whole package of cookies or a block of cheese. Of individuals with restrictions, 38% of them did not have the restriction noted on their plan.

10. Who decides what you wear?

    Individuals responding to this question indicated that 89% of adults receiving services decided what they wore each day. The reasons for 11% of people not choosing their clothes included statements like, "does not care what he wears," "unable to make a choice," or "needs to make weather appropriate choices."

11. Do you choose how to spend your money?

    Regarding how money is spent, 93% of the respondents acknowledged that the adult recipient chose how to spend their money with support. According to respondents, a person's money was typically specified as their "allowance." Support for spending was defined as "managing money," "helping to pay the bills first," "requiring supervision when spending money," and staff or agency "keeps or holds the money." Only 7% of the respondents indicated that the adult did not choose how to spend their money. Reasons given included comments like "they don't understand money," "the family chooses based on individual's likes," and that "guardians had to approve spending."

12. Do you have a TV in your house?

    All respondents indicated that there was a television in the house.

13. Can you watch TV whenever you want to?

Respondents to this question indicated that 90% of the adults receiving services were able to watch TV when they wanted to. There were 10% of individuals who had some restrictions. These restrictions included turning off the TV because it was “bedtime” or for health reasons in that “he would stay up all night watching TV.”

None of the individuals had a TV restriction noted in their Individual Support Plan.

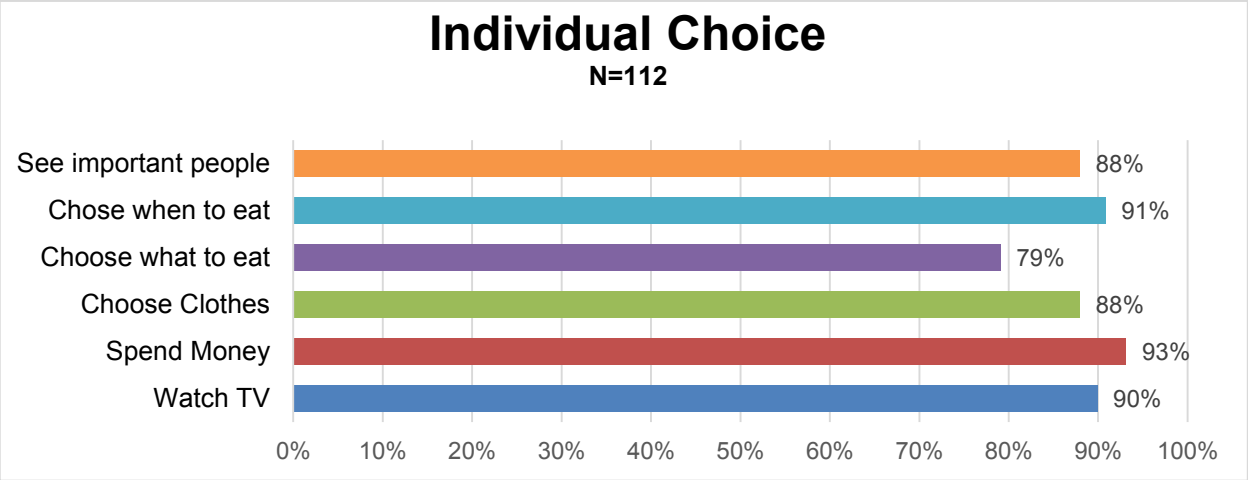



Figure 5

**Category C: Employment**

14. Do you have a job?

The results of the study revealed that 72% of adults receiving services were not employed. Of the adults who were employed, 19 were employed in the community between 1-20 hours per week, and 12 were employed in a DD/sheltered workshop between 4-12 hours a week. With regards to paid employment, 52% of people working were paid minimum wage or above, and 13% were paid below minimum wage. The remaining 35% were not sure if they were paid or could not remember how much they were paid. Work settings included cleaning in a hotel, janitorial work in a school or business, tasks at Goodwill, and a detail painter at a sheltered workshop.

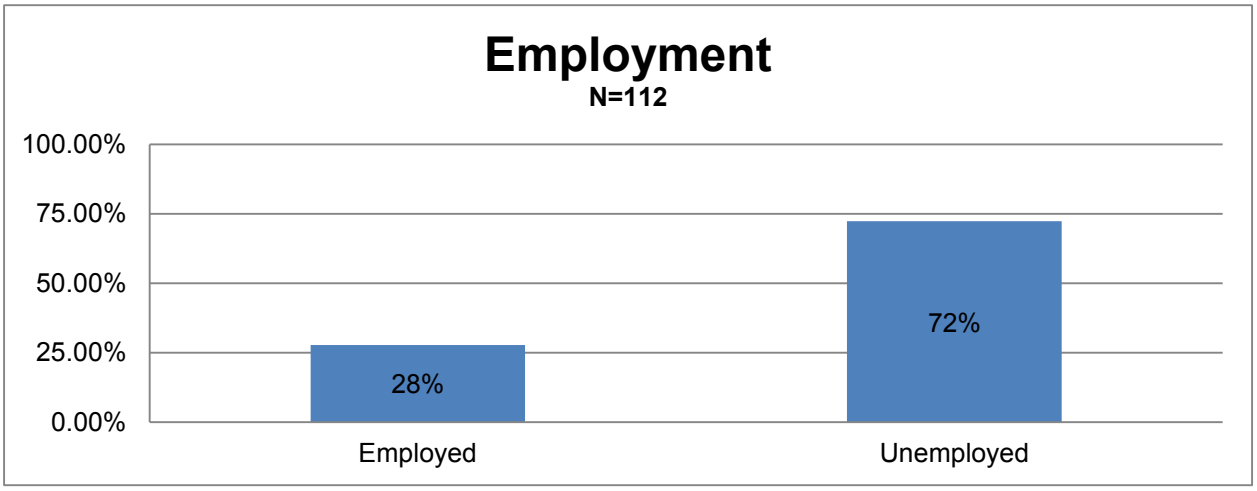



Figure 6

**Category D: Integration into the Community**

15. When you leave your house, what do you like to do?

Adults receiving services and/or their guardians or support personnel had various answers to this question. The answers were not different across the state. Typical answers included shopping, bowling, going to movies, going out to eat, walking, and going to thrift stores.

Respondents indicated that 83% of adult recipients made decisions as to what they wanted to do each day. Some individuals received input from family members or support personnel to help create daily and weekly schedules, some of which included an activity that took place in the community. Limitations for community activities might include the issue of "time" in that people needed transportation or support and a family member or support person was not available at particular times of the day or week.

**Category E: Personalized Plan**

This category focused on the development of an individual's Person Centered Plan. The interviews included core questions regarding the plan but also included follow-up questions to provide additional detail about the process. As with all of the questions, the answers provided were from the perspective of the recipient, a guardian, or a support person.

16. Are you familiar with your person-centered plan?

The results of the study indicated that 77% of respondents were familiar with their plan and 23% of respondents were not familiar with the plan. The majority of people interviewed did not recognize the term "person centered plan" but rather "individual support plan."

17. Do you attend your annual person-centered planning meeting?

Responses to this question indicated that 94% of adult recipients attend their person centered planning meeting. Responses for the 6% of people that do not attend included:

- "The agency goes to the planning meeting."
- "I know the plan is in my book. I just know mom makes it and they just tell me some stuff I need to follow and that's what I follow. Scheduling and stuff like that."
- "We have a little meeting without him and we talk over what's going on. Then he is brought in and we go back over everything."
- "It would be too distressing for him to have to sit for that meeting."
- "There's so much stuff they talk about, it's mind boggling."

Respondents were asked a follow up question about how the adult recipient participated in the meeting. The majority of people were asked a series of questions. The process did not appear to be adapted for recipients who had various support needs. For example, adjusting questions for language level, time needed to process information, or the experience of the recipient.

For example:

- “When I’m at (agency name) I attend the meeting but they don’t really tell me what my plans are. They just tell me, ‘This is what’s going to happen’. I go to the meeting, it’s just, that they tell me this is what my plan’s going to be.”
- “He just agrees.”
- “She participates by answering ‘yes’ and ‘no’ questions.”
- “She just listens.”
- “Usually I am running the show. I have some chatty Cathy’s in my workers and so we’ll get lost because I’ll get overwhelmed and I’m like ‘Okay, I just want this over and done with’ and so we’ll speed along and kind of forget. But usually on a good day we’ll talk about ‘Well, what do you think you need help in this area? You have improved in this area. Do you think that needs to be worked on?’”

People who typically attended a meeting were the adults receiving HCBS, family members, support staff, Targeted Service Coordinators, support brokers, or agency staff. With regards to choosing attendees, 96% of adult recipients answering questions in this category said they had invited the people at their last meeting and knew they could choose the people who attend a meeting.

18. Are you asked about your strengths/abilities during the meeting?

-and-

19. Are you asked about your preferences/likes during the meeting?

Final Medicaid HCBS rules include changes to the requirements regarding person-centered plans for HCBS waivers under 1915 (c) and HCBS state plan benefits under 1915 (i) and “identifies the strengths, preferences, needs (clinical and support), and desired outcomes of the individual.”

The document entitled, “Person Centered Planning Process and Plan Requirements” (Appendix C) is distributed by the Idaho Department of Health and Welfare to reflect the components of the federal requirement for a person centered plan. That document includes the HCBS rule language and states that a plan must “Reflect the individual’s strengths and preferences.”

To discover how this requirement was currently being met, the interview included a question about strengths and preferences.

The results of the study indicated that only one person out of the 112 recipients was asked about their strengths and preferences to subsequently use in the person centered planning process. The one individual was on self-direction and “loves music” so the plan included music therapy.

There was a pattern across the state on the topics of strengths and preferences. Professionals, individuals, or guardians did not appear to understand why the questions were being asked or how they might be used to develop a plan. For example, when a support person was asked if the individual’s strengths were discussed at the meeting

she said, “Yep. Happy all the time for the most part. She loves to socialize.” When asked if the woman’s likes were discussed she responded, “Yes, she loves animals, Elvis, and she loves to interact with people.”

Even though there had been a discussion about this individual’s strengths and preferences her goals included “stretches, to be able to cook her food, to use the sign ‘toilet,’ to go to the YMCA at least once a week, and to ‘put away her clean clothes.’”

Another young woman was asked about her “likes” and she responded:

- “I like color. I like music. I like to be socially active. I like being with my friends a lot. I like being with my animals. I like volunteering, doing crafts and helping out with local communities.”

This young lady’s goals included “meal planning, budgeting, and coping skills.”

Other comments included:

- “I think her abilities are - that’s one of the things that we’re strongly working on is her understanding money and her having some strong life skills. What can she do and what she can’t do. I think her abilities are that she can be given three step or five step commands.”
- “We have to talk about his likes. That’s one of the requirements that they have to fill in for the ISP is things that he likes or does not like.”
- “We do, but kind of talk between us usually when we do it. Because if we ask her she’ll just answer ‘yes’ most of the time unless I do a ‘yes/no’. So when you ask her what her strengths are its kind of hard because it’s not a one or two answers to a question. It’s a long list of things she works on throughout the year. We have been working on pain/hurt for the past 24 years. She works on identifying colors and shapes, the basic kind of stuff.”

The interpretation of a person’s “strengths” from both the professional and family perspective seemed to be defined as an update on how a person was performing on a program rather than reflecting the abilities a person has that could then be used to develop goals on a plan. For example, one young man liked taking pictures and volunteers at the library and food pantry in his community. “He takes pictures all the time and sometimes the local newspaper will publish them,” said his guardian, “he does pictures for the county fair and so he’s got ribbons and stuff in there for his own pictures.”

This young man’s goals include “volunteer and making sure he can fill out a timesheet, as well as talking with complete words and sentences.”

20. <u>Do you know the goals in your plan?</u>

The final question on the interview asked recipients about the goals on their plan. There were follow up questions regarding community based and work goals as well as how the goals were decided. The results of the study indicated that 34% of respondents did not remember the goals on the recipient’s plan.

There were some themes across plans. For example, 25% of people in the study had a "budgeting" or "learning to manage money" goal. Other popular goals included hygiene, cooking, cleaning, safety, living a healthy life, and meal planning.

Respondents also talked about a recipient's participation in community goals in different ways. For example, for some people the community was a place to "build a skill" such as learning how to use an ATM machine. For other people it was about "social interactions" or "learning where different resources are and what they have to offer you." Other community goals included "safety goals like asking help from a clerk", "stranger awareness", or "price comparison."

Not everyone had a specific community based goal or if they did the respondent did not always remember the goal. The definition of community was also defined in different ways depending upon the "support" needed by the recipient. For example, for some people "community" was defined as the day program at the DD agency.

Follow-up questions were also included regarding work and pre-vocational goals. Of the people who were interviewed only two recipients had a work goal on their plan. There was no one who had a "pre-vocational" goal on their plan in any region of the state. Getting a job seemed to be interpreted in a more traditional manner where people work 40 hours a week rather than looking at customizing work experiences to fit the abilities and contributions of the individual.

The Process of Developing Goals

Most meetings included someone, either the adult recipient or the guardian, being asked a series of questions. The themes across the state revealed similar goals for adult recipients in every region. Additionally, the goals were developed from a more deficit based perspective "things I need to work on" or "things I'm not good at" rather than reflecting a recipient's strengths and preferences to develop a plan.

- "SIB-R is done at the same time as the meeting. They then ask her to leave the room. Attendees include mostly her staff (Targeted service coordinator, support person, program coordinator). They then sit down and ask her what programs she wants to have. If there's anything new they write it down."

Some plans were developed using previous plans:

- "Well, we usually take the plan from last year. What's worked and what hasn't. Hopefully, like I said I'd like to have some of the staff there that are actually working with him because they can actually say 'this isn't working at all.' But we try and update."

Some plans were developed using other people's plans:

- "I didn't know what I was doing and I didn't get too much direction, so I got a copy of another person's and kind of went with that because I didn't have any idea."

Some plans were based on perceived needs:

- "It's things that I need to work on that I'm not doing so well on. So we try to make that a goal. So after a certain amount of time if I've reach a certain point we can take that off or we can continue with it."

Some plans were developed by other people besides the recipient:

- “No, they just say ‘this is what he needs to work on.’ They just say to take him to what he likes to do. It’s like a reward system.”

Some plans were not based on anything in particular:

- “We throw things at the wall and see what sticks.”

Respondents said that goals were typically developed from a series of questions that were to be answered by the recipient or their guardian. Goals were also developed from assessments (e.g., SIB-R) that were perceived as skills that people “needed to learn.” However, these things appeared to be goals that were not necessarily leading to an outcome. For example, a person might have a goal on their plan to fill out a time sheet but did not have a job or a work or a pre-vocational goal.

The plans of people who had more complex disabilities and were designated at the extensive and pervasive levels of support typically had goals that did not reflect many or few high expectations. People were simply “being taken care of” with little recognition of competency or active participation in work and community activities. The overall sense was that people, both professionals and guardians, did not think about or know how to customize plans to create future outcomes for people at various support levels.

## Summary

The study involved a range of people at five support levels on the SIB-R. These were people as young as 18 and as old as 68. They lived in certified family homes, supported living situations, or by themselves or with family. Sixty percent of recipients either had support from another person in answering the interview questions or the questions were answered entirely by a support person with no active involvement by the focus individual. It became apparent as the study progressed that the process of developing the plan was the same no matter the level of support. It was also clear that according to the people who were interviewed, the process was not adapted to accommodate for individual needs. For example, a young man said, “Yes, I don’t usually pay attention to those. I usually nod off because they are using a bunch of big words that I’ll never understand even if I tried. I go and usually later on have my staff explain it to me in a non-fast paced way because usually they’re doing it at a fast pace and I can’t keep up.”

The results of the study indicated that the format of a planning meeting included gathering information by asking questions and subsequently having recipients make choices about their goals. The challenge of conducting meetings using a verbal format is that people who have a range of disabilities and support levels also range in how they understand and process information. Best practice would suggest that accommodations for a diverse group of people would include variables like pacing of the conversation, language level and terminology, factoring in sensory issues, remembering that people with intellectual disabilities can have issues with the concept of “time,” and understanding people’s experience well enough to know if they are making an informed choice.

## Limitations of the Study

Time

Each interview was conducted in less than an hour. This short period of time did not give the researchers any quality time to get to know the recipient, a guardian, or support person. Researchers did not have an opportunity to conduct any observations to confirm a recipient's experience within a home or community setting.

Missing Data

The list provided by the Department of Health and Welfare contained incomplete and/or outdated information for recipients and their guardians. The researchers were unable to contact 18% of potential participants for reasons including wrong address, disconnected, outdated, or 'wrong' phone numbers, changes in guardianship, and recipients who were now deceased.

"Just another socialist program"

Another limitation of the study was that some guardians and/or professional staff seemed to be wary of the researchers and the interview. Even though they had been given information about the purpose of the study and had signed consent forms there remained a level of skepticism in answering questions. In particular, respondents from certified family homes made comments such as "Why do they want to know that"? or "We don't want to participate in anything having to do with the Department any more than necessary." This attitude may have impacted the validity of a response in that people were afraid their answer would reflect upon them as a care provider.

Verification of information

The researchers did not have access to any of the recipients' person centered plans. They did not see specific goals or any notes made on the document but relied on the perceptions of the individual receiving services, a guardian, or professional staff.

Perception of disability

The complexity of a recipient's disability impacted the research at two points. First, there were guardians who did not want to participate in an interview due to their perception of their son or daughter's disability. Comments such as, "Honey, that would be a waste of your time and mine" or "She is at a three-year-old level" were the kinds of comments that occurred in all seven regions. This perception impacted the number of people who participated in the study.

## 5 Key Findings

## "Choice and Community: Seeking the Voice of Adults with Developmental Disabilities"

1. The perceptions of adult recipients of Home and Community Based Services or their guardians indicate they had adequate choice within their living situations.

2. The majority of recipients who had some kind of restriction related to what they could eat or when they could watch television did not have that restriction listed on their plan.

3. Recipients of Home and Community Based Services were not employed. They did not have a work or pre-vocational goal listed on their plan.

4. The person centered planning process developed goals that did not reflect a recipient's strengths and preferences.

5. The person centered planning process did not accommodate the diversity of recipients of Home and Community Based Services.

# Appendix A

| County Number | County FIPS | County | Region | Region Num | Geo Density | 2015 Population | Land area sq miles | Population per Sq miles |
|---|---|---|---|---|---|---|---|---|
| 1 | 1 | Ada | Region 4 | 4 | Urban | 434,211 | 1,053 | 412.4 |
| 2 | 3 | Adams | Region 3 | 3 | Frontier | 3,843 | 1,363 | 2.8 |
| 3 | 5 | Bannock | Region 6 | 6 | Urban | 83,744 | 1,112 | 75.3 |
| 4 | 7 | Bear Lake | Region 6 | 6 | Frontier | 5,922 | 975 | 6.1 |
| 5 | 9 | Benewah | Region 1 | 1 | Rural | 9,052 | 777 | 11.6 |
| 6 | 11 | Bingham | Region 6 | 6 | Rural | 44,990 | 2,094 | 21.5 |
| 7 | 13 | Blaine | Region 5 | 5 | Rural | 21,592 | 2,644 | 8.2 |
| 8 | 15 | Boise | Region 4 | 4 | Frontier | 7,058 | 1,899 | 3.7 |
| 9 | 17 | Bonner | Region 1 | 1 | Rural | 41,859 | 1,735 | 24.1 |
| 10 | 19 | Bonneville | Region 7 | 7 | Urban | 110,089 | 1,866 | 59.0 |
| 11 | 21 | Boundary | Region 1 | 1 | Rural | 11,318 | 1,269 | 8.9 |
| 12 | 23 | Butte | Region 7 | 7 | Frontier | 2,501 | 2,232 | 1.1 |
| 13 | 25 | Camas | Region 5 | 5 | Frontier | 1,066 | 1,074 | 1.0 |
| 14 | 27 | Canyon | Region 3 | 3 | Urban | 207,478 | 587 | 353.5 |
| 15 | 29 | Caribou | Region 6 | 6 | Frontier | 6,770 | 1,764 | 3.8 |
| 16 | 31 | Cassia | Region 5 | 5 | Rural | 23,506 | 2,565 | 9.2 |
| 17 | 33 | Clark | Region 7 | 7 | Frontier | 880 | 1,764 | 0.5 |
| 18 | 35 | Clearwater | Region 2 | 2 | Frontier | 8,496 | 2,457 | 3.5 |
| 19 | 37 | Custer | Region 7 | 7 | Frontier | 4,087 | 4,921 | 0.8 |
| 20 | 39 | Elmore | Region 4 | 4 | Rural | 25,876 | 3,075 | 8.4 |
| 21 | 41 | Franklin | Region 6 | 6 | Rural | 13,074 | 664 | 19.7 |
| 22 | 43 | Fremont | Region 7 | 7 | Frontier | 12,819 | 1,864 | 6.9 |
| 23 | 45 | Gem | Region 3 | 3 | Rural | 16,852 | 561 | 30.0 |
| 24 | 47 | Gooding | Region 5 | 5 | Rural | 15,284 | 729 | 21.0 |
| 25 | 49 | Idaho | Region 2 | 2 | Frontier | 16,272 | 8,477 | 1.9 |
| 26 | 51 | Jefferson | Region 7 | 7 | Rural | 27,157 | 1,094 | 24.8 |
| 27 | 53 | Jerome | Region 5 | 5 | Rural | 22,814 | 597 | 38.2 |
| 28 | 55 | Kootenai | Region 1 | 1 | Urban | 150,346 | 1,244 | 120.9 |
| 29 | 57 | Latah | Region 2 | 2 | Urban | 38,778 | 1,076 | 36.0 |
| 30 | 59 | Lemhi | Region 7 | 7 | Frontier | 7,735 | 4,563 | 1.7 |
| 31 | 61 | Lewis | Region 2 | 2 | Rural | 3,789 | 479 | 7.9 |
| 32 | 63 | Lincoln | Region 5 | 5 | Frontier | 5,297 | 1,201 | 4.4 |
| 33 | 65 | Madison | Region 7 | 7 | Urban | 38,273 | 469 | 81.6 |
| 34 | 67 | Minidoka | Region 5 | 5 | Rural | 20,461 | 758 | 27.0 |
| 35 | 69 | Nez Perce | Region 2 | 2 | Urban | 40,048 | 848 | 47.2 |
| 36 | 71 | Oneida | Region 6 | 6 | Frontier | 4,281 | 1,200 | 3.6 |
| 37 | 73 | Owyhee | Region 3 | 3 | Frontier | 11,310 | 7,666 | 1.5 |
| 38 | 75 | Payette | Region 3 | 3 | Rural | 22,896 | 407 | 56.3 |
| 39 | 77 | Power | Region 6 | 6 | Frontier | 7,648 | 1,404 | 5.4 |
| 40 | 79 | Shoshone | Region 1 | 1 | Frontier | 12,432 | 2,630 | 4.7 |
| 41 | 81 | Teton | Region 7 | 7 | Rural | 10,564 | 449 | 23.5 |
| 42 | 83 | Twin Falls | Region 5 | 5 | Urban | 82,375 | 1,921 | 42.9 |
| 43 | 85 | Valley | Region 4 | 4 | Frontier | 10,103 | 3,665 | 2.8 |
| 44 | 87 | Washington | Region 3 | 3 | Frontier | 9,984 | 1,453 | 6.9 |

Idaho Department of Health and Welfare (2016). Idaho County Geodemographic data. Unpublished internal document.

| Cnty Type | Number of Sq Miles | 2015 Population Count | Percent of Sq Miles | Percent of Population |
|---|---|---|---|---|
| Frontier | 52,572 | 138,504 | 64% | 8% |
| Rural | 19,897 | 331,084 | 24% | 20% |
| Urban | 10,176 | 1,185,342 | 12% | 72% |
| Total | 82,645 | 1,654,930 | 100% | 100% |

Geo Density Criteria:
Urban counties have a population center of at least 20,000.
Rural counties have at > = 7 people per square mile and no population centers larger than 19,999.
Frontier counties have < 7people per square mile and no population centers larger than 19,999.

Counties w population center of 20,000 or more

1 Ada
2 Bannock
3 Bonneville
4 Canyon
5 Kootenai
6 Latah
7 Madison
8 Nez Perce
9 Twin Falls

| CountyN | NAME | POPESTIMATE2014 |
|---|---|---|
| Ada | Boise City city | 216282 |
| Ada | Eagle city | 22502 |
| Ada | Meridian city | 87743 |
| Bannock | Pocatello city (pt.) | 54278 |
| Bonneville | Idaho Falls city | 58691 |
| Canyon | Caldwell city | 50224 |
| Canyon | Nampa city | 88211 |
| Kootenai | Coeur d'Alene city | 47912 |
| Kootenai | Post Falls city | 29896 |
| Latah | Moscow city | 24767 |
| Madison | Rexburg city | 27094 |
| Nez Perce | Lewiston city | 32482 |
| Twin Falls | Twin Falls city | 46528 |

# Appendix B

# Interview Protocol

Date:

Place:

Interviewer

Interviewee Information

- Age
- Sex
- Living situation (Certified Family Home/Supported Living/Self Direction/Other)

(Describe the (a) purpose of the study, (b) individuals and sources of data being collected, (c) what is being done with the data to protect the confidentiality of the interviewee, and (d) how long the interview will take.)

**Questions**:

**Category A: Living Situation**

1. Do you have a room of your own?
2. Do you have a roommate or housemate?
3. If you have a roommate, did you get to choose him/her?
4. Can you be by yourself if you want to/Can you be alone if you want to?
5. If you are in your bedroom, do people come in without asking first?
6. Do you get the privacy you want when you get dressed, use the bathroom, or shower?

**Category B: Individualized Choice**

7. Are you able to see people that are important to you whenever you want to?
    a. People who matter to you, etc.
    b. Reasons… scheduling problems? Distance?
8. Do you get to eat when you want to?
9. Do you choose what you eat?
    a. If no, is the diet restriction included in your personalized plan?
    b. If meal planning, are you a part of the weekly planning?
        i. If no, are you aware it should be?
10. Who decides what clothes you wear?
11. Do you choose how to spend your money?
12. Do you have a TV in the house? Where is it?
13. Can you watch TV whenever you want to?
    a. If no, is the restriction included in your personalized plan?
        i. If no, are you aware it should be?

**Category C: Employment**

14. Do you have a job?
    a. If yes, where do you work?
        i. What do you do?
        ii. Are you paid?
            1. How much?
        iii. How many hours a week?
    b. If no, would you like a job or has anyone talked to you about working?

**Category D: Integration into the Community**

15. When you leave your house, what do you like to do?
    a. How do you decide what to do?
    b. Who decides when you do those things?

**Category E: Personalized Plan**

16. Are you familiar with your person centered plan?
17. Do you attend your annual person centered planning meeting?
    a. Do you participate?
        i. How?
    b. Who attends those meetings?
        i. Did you choose those people?
            1. Are you aware you can choose who is in attendance?
18. Are you asked about your strengths/abilities during the meeting?
19. Are you asked about your preferences/likes during the meeting?
    **a. ***What are you good at? Vs What do you like to do?*****
20. Do you know the goals in your plan- what are they?
    a. Do you have any community-based goals?
    b. Do you have a ‘work’ goal?
        i. If no, is there a pre-vocational goal?
    c. How were they decided?

# Appendix C

# Person Centered Planning Process and Plan Requirements

| **Person-Centered Planning Process** |
|---|
| The individual will lead the person-centered planning process where possible. The individual's representative should have a participatory role, as needed and as defined by the individual, unless State law confers decision-making authority to the legal representative. All references to individuals include the role of the individual's representative. In addition to being led by the individual receiving services and supports, the person-centered planning process: |
| • Includes people chosen by the individual |
| • Provides necessary information and support to ensure that the individual directs the process to the maximum extent possible, and is enabled to make informed choices and decisions. |
| • Is timely and occurs at times and locations of convenience to the individual. |
| • Reflects cultural considerations of the individual and is conducted by providing information in plain language and in a manner that is accessible to individuals with disabilities and persons who are limited English proficient, consistent with § 435.905(b) of this chapter. |
| • Includes strategies for solving conflict or disagreement within the process, including clear conflict-of-interest guidelines for all planning participants. |
| • Providers of HCBS for the individual, or those who have an interest in or are employed by a provider of HCBS for the individual must not provide case management or develop the person-centered service plan, except when the State demonstrates that the only willing and qualified entity to provide case management and/or develop person-centered service plans in a geographic area also provides HCBS. In these cases, the State must devise conflict of interest protections including separation of entity and provider functions within provider entities, which must be approved by CMS. Individuals must be provided with a clear and accessible alternative dispute resolution process. |
| • Offers informed choices to the individual regarding the services and supports they receive and from whom. |
| • Includes a method for the individual to request updates to the plan as needed |
| • Records the alternative home and community-based settings that were considered by the individual. |

| **Person-Centered Service Plan** |
|---|
| The person-centered service plan must reflect the services and supports that are important for the individual to meet the needs identified through an assessment of functional need, as well as what is important to the individual with regard to preferences for the delivery of such services and supports. Commensurate with the level of need of the individual, and the scope of services and supports available under the State's 1915(c) HCBS waiver, the written plan must: |
| • Reflect that the setting in which the individual resides is chosen by the individual. The State must ensure that the setting chosen by the individual is integrated in, and supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS. |
| • Reflect the individual's strengths and preferences. |



Idaho Department of Health and Welfare (2015). Person Centered Planning Process and Plan Requirements. Unpublished internal document.

| |
|---|
| • Reflect clinical and support needs as identified through an assessment of functional need. |
| • Include individually identified goals and desired outcomes. |
| • Reflect the services and supports (paid and unpaid) that will assist the individual to achieve identified goals, and the providers of those services and supports, including natural supports. Natural supports are unpaid supports that are provided voluntarily to the individual in lieu of 1915(c) HCBS waiver services and supports. |
| • Reflect risk factors and measures in place to minimize them, including individualized back-up plans and strategies when needed. |
| • Be understandable to the individual receiving services and supports, and the individuals important in supporting him or her. At a minimum, for the written plan to be understandable, it must be written in plain language and in a manner that is accessible to individuals with disabilities and persons who are limited English proficient, consistent with § 435.905(b) of this chapter. |
| • Identify the individual and/or entity responsible for monitoring the plan. |
| • Be finalized and agreed to, with the informed consent of the individual in writing, and signed by all individuals and providers responsible for its implementation. |
| • Be distributed to the individual and other people involved in the plan. |
| • Include those services, the purpose or control of which the individual elects to self-direct. |
| • Prevent the provision of unnecessary or inappropriate services and supports. |
| • Document that any modification of the additional conditions, under paragraph (c)(4)(vi)(A) through (D) of this section, must be supported by a specific assessed need and justified in the person-centered service plan. The following requirements must be documented in the person-centered service plan: |
| (A) Identify a specific and individualized assessed need. |
| (B) Document the positive interventions and supports used prior to any modifications to the person-centered service plan. |
| (C) Document less intrusive methods of meeting the need that have been tried but did not work. |
| (D) Include a clear description of the condition that is directly proportionate to the specific assessed need. |
| (E) Include a regular collection and review of data to measure the ongoing effectiveness of the modification. |
| (F) Include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated. |
| (G) Include informed consent of the individual. |
| (H) Include an assurance that interventions and supports will cause no harm to the individual. |

**Review of the Person-Centered Service Plan.**

The person-centered service plan must be reviewed, and revised upon reassessment of functional need as required by § 441.365(e), at least every 12 months, when the individual's circumstances or needs change significantly, or at the request of the individual.



Idaho Department of Health and Welfare (2015). Person Centered Planning Process and Plan Requirements. Unpublished internal document.

## References


Bruininks, R.H., Woodcock, R.W., Weatherman, R.E., & Hill, B.K. (1996). *Scales of Independent Behavior – Revised (SIB-R)*. Rolling Meadows, IL: Riverside Publishing.

Idaho Department of Health and Welfare (2016). *Idaho County Geodemographic data*. Unpublished internal document.

Idaho Department of Health and Welfare (2015). *Person Centered Planning Process and Plan Requirements.* Unpublished internal document.

Medicaid Program; *State Plan Home and Community-Based Services, 5-year Period for Waivers, Provider Payment Reassignment, and Home and Community-Based Setting Requirements for Community First Choice and Home and Community-Based Services (HCBS) Waivers*, 42 C.F.R § 430, 431, 435, 436, 440, 441, & 447 (2014).

# 2016-2017 Quarterly Council Meeting Dates

## Background Information:

Pursuant to state law and Council by-law, the Council shall meet (in person, by conference call or video conferencing) at least once during each federal fiscal quarter. A yearly calendar of dates for the upcoming fiscal year shall be established by the fourth (4th) quarter meeting. Please prepare by bringing scheduled dates of known meetings of other councils, committees, and groups.

## Recommended Action:

Decide meeting dates for 2016-2017.

## Recommended Action:

Bring calendars, any known meeting dates, or schedule conflicts

## Notes:

# 3rd Quarter Progress Report

## Background Information:

The Council has a number of objectives and activities in the current annual plan. Some are part of large projects and some are ongoing smaller efforts. This is an opportunity to share the highlights of progress on our plan goals during quarter three of this year – April 1st – June 30th.

## Recommended Action:

Listen to the updates and ask questions or provide comments if you have them. Council members who are involved with any of this work are encouraged to offer their insights.

## Notes:

The Third Quarter Progress Report will be provided at the meeting.

## 1.1 Inclusive Education-Teacher Certification

Objective Goal **Develop a comprehensive plan that describes how we will change teacher certification in the coming years.**

Progress

Inclusive Education Task Force

- No work has been done this quarter on this objective

Outcomes/Work Products:

- Draft of strategic plan

Attention Areas/Challenges

- Plan moved closer to objective to have more Idaho teachers feel comfortable educating all students in the regular classroom

Resources – What Helps to Make It Happen/What is Needed

- Staff time to meet with stakeholders
- Connections to right people
- Funds to bring people together to build strategy and final plan

Schedule

Project is on track to achieve objective by the end of 5-year plan.

## 1.2 Inclusive Education-Technical Assistance and Awareness

Objective Goal **Begin to develop a plan for professional development and technical assistance to help schools implement evidence-based inclusion practices.**

### Progress

Meetings and Awareness Presentations

- Collaborative presentation at local elementary school on importance of inclusive practices: 27 individuals reached
- Continued work on **Universal Design for Learning (UDL) Symposium** – Saturday, September 10, 2016
- Presentation at *Teach for America* candidate training: 15 teachers
- Face-to-face meetings with teachers to promote UDL Symposium
- Promotion of UDL Symposium through State Dept. of Ed website

### Outcomes/Work Products:

- Letter of Agreement drafted and sent to keynote speaker, Dr. Joy Zabala from CAST
- Coordination of details for UDL Symposium
- Promotion materials for Symposium
- Teachers educated on the importance of inclusive practices in schools

### Attention Areas/Challenges

- School districts have limited resources for professional development
- Time commitment for staff

### Resources – What Helps to Make It Happen/What is Needed

- Staff time to meet with stakeholders to begin plan development
- Funds to bring people together to identify doable strategies

### Schedule

Objective may be achieved by the end of 5-year plan.

## 1.3 Employment First Initiative and Employment Training

Objective Goal Create more opportunities for people with developmental disabilities to have jobs in the community **by working with partners on a statewide employment first project that includes educating communities, training staff, and writing at least one state policy to improve services**

### Progress

Employment First Consortium

- Monthly meetings with Employment First Consortium
- Employment services cost survey completed by 21 provider agencies and data compiled to be reviewed at July meeting
- Recommendations from Provider Qualifications Workgroup
- Participation in 3 webinars and 2 Community-of-Practice Phone Calls
- Work began on Partnership in Employment Systems Change grant from the Administration on Community Living
- Participation in meetings with Idaho Vocational Rehabilitation on technical assistance around Workforce Innovation and Opportunities Act (WIOA)

### Outcomes/Work Products:

- IEFC members involved in policy discussions and recommendations for Medicaid services policy development
- Draft grant proposal
- Council input on planning and issues related to sub-minimum wage

### Attention Areas/Challenges

- Discussions and MOU's with required partners for Partnership in Employment Systems Change grant

### Resources – What Helps to Make It Happen/What is Needed

- Staff time to coordinate and Council funds needed to host IEFC meetings/communication and develop materials
- Staff time gathering all necessary agreements and information for grant

### Schedule

Project is on track to achieve objective by the end of 5-year plan.

## 1.4 Disability Mentoring Day

Objective Goal **Work with others to support Disability Mentoring Day in at least 3 communities each year to** help youth find out about jobs in their communities**.**

Progress

- All reports received, reviewed and documented

Schedule

Project is on track: *Objective is achieved as the Council provides funds each year to local DMD projects.*

## 1.5 Direct Support Staff Training

Objective Goal Increase the quality of support staff **by providing or supporting training that builds the skills and knowledge of up to 200 direct support staff each year.**

Progress

Employment Support Professionals – Training and Qualifications

- Finalize support professionals competency recommendations
- Recommendations developed regarding competencies needed to provide quality pre-vocational, career planning and individual supported employment services
- Recommendations align with customized employment competencies adopted by Association of People Supporting Employment First (APSE) and as recommended by the Office on Disability Employment Policy

Outcomes/Work Products:

- Provider Qualifications Workgroup engaged in policy discussions
- Recommendations for qualifications and training to the Idaho Employment First Consortium (IEFC)

Attention Areas/Challenges

- Increase connection to direct support staff with agencies around the state, seek service provider buy-in to increase qualifications and training

### Resources – What Helps to Make It Happen/What is Needed

- Council funds to support workgroup
- Connection to WIOA partners and local stakeholders to continue interest in Discovery and customized employment
- Staff time to continue outreach and gather information

### Schedule

Project is on track: Objective is achieved as the Council supports training each year for direct support staff in any system.

## 1.6 DD Services System Change

Objective Goal **Work with partners on service system changes to** improve access to individualized developmental disability services **in Idaho communities.**

### Progress

Therapeutic Stabilization Center

- Participation in stakeholder meetings throughout the quarter to discuss potential stabilization center to replace Southwest Idaho Treatment Center (SWITC)
- Participate in meetings and conversations about best practice intervention for individuals with high support needs and who have a dual diagnosis

Behavioral Health Medicaid Managed Care Contract: Optum

- Quarterly meetings as part of the Consortium of Idahoans with Disabilities (CID) to continue discussions regarding on-going issues with the Medicaid Managed Care Contract for Behavioral Health

Achieving a Better Life Experience (ABLE) Accounts

- Participation in ABLE Act stakeholder committee
- White paper written and distributed to stakeholders
- On-going conversations with families and individuals regarding the need for technical assistance in Idaho around ABLE Accounts
- Work with stakeholders to prepare for 2017 legislation

National Core Indicator Data (NCI)

- Co-sponsored distribution of questionnaire to families with children with disabilities: 1000 surveys returned; high response from Spanish-speaking families
- Continue as a stakeholder in work with the Division of Family and Community Services (FACS) on the pursuit of adult NCI data collection

K.W. vs. Armstrong Lawsuit

- Continued collaboration with American Civil Liberties Union (ACLU) to provide input on Department of Health and Welfare's plan to address issues named in the lawsuit

Statewide Study of Adults with Developmental Disabilities on the DD Waiver

- Collaboration on the statewide study, review of results, and application of what was learned for work within the five year plan

## Outcomes:

- CWG meeting focused on improving quality in person centered planning processes and in transitioning service delivery using person centered thinking approaches
- Input in best practices in serving individuals with developmental disabilities who have intense support needs and dual diagnosis
- Continue efforts to improve outcomes for those with a dual diagnosis accessing mental health services in Idaho
- White paper written and distributed on ABLE account TA position
- Data collection from families regarding children's services through the National Core Indicator (NCI) data collection project.
- Report Choice and Community: Seeking the Voice of Adults with Developmental Disabilities a collaborative statewide study through the Center on Disabilities and Human Development and the Idaho Council on Developmental Disabilities

## Attention Areas/Challenges

-Staff resources to provide thoughtful comment with the many state changes

## Resources – What Helps to Make It Happen

- Council funds to support facilitation contract (for CWG meetings)
- Staff time to help coordinate CWG communication, research information, and develop materials
- Good relationships with stakeholders/partners
- Staff committed to specific work related to CWG work products (surveys of individuals, data collection, statewide focus groups to survey adults with developmental disabilities and families, database development, reports)
- Partnership with the Center on Disabilities and Human Development and the Department of Health & Welfare on the statewide HCBS study
- Partnership with Health and Welfare and CDHD on NCI study
- Staff time in meetings, drafting information and gathering information from stakeholders

## Schedule

Project is on track to achieve objective by the end of 5-year plan.

## 2.1 Self Advocacy Organization

Objective Goal **Provide money each year to** support one statewide self-advocacy organization **led by people with disabilities**

Progress

Idaho Self Advocate Leadership Network - Contract

- Idaho SALN contract with the Council was canceled as of May 15, 2016 due to lack of progress towards outcomes
- SALN is a non-profit organization and can seek funding from other sources to continue working on self-advocacy in Idaho

Outcomes/Work Products:

- No outcome reports were received from SALN for Quarter 3 (Jan – March 2016)

Attention Areas/Challenges

- Changes in leadership of State Board
- Resignation of State Coordinator (March)
- Contract scope of work and quarterly reports
- Chapter model / lack of support locally
- Member desire for work on public policy issues in Idaho and member desire to provide social opportunities

Resources – What Helps to Make It Happen/What is Needed

- Council funds to support contract (until May 14, 2016)
- Staff time to monitor contract
- Support from other agencies/organizations

Schedule

Project is on track:
Objective is achieved as the Council provides funds each year to Idaho SALN.

## 2.2 Statewide Self Advocacy Conference

**COMPLETED**: Objective was achieved in year two of the strategic plan.

## 2.3 Self Advocacy Training Support

Objective Goal **<u>Support self-advocate leaders</u> each year to** provide and/or receive leadership development training

### Progress

<u>Self-Advocates Requesting Support for Leadership Development Training</u>

- The presentation on Supported Decision Making by Jenny Hatch was held in May 2016 Magistrate Judges conference in Coeur d'Alene. $1,500 in Council funds were utilized to support Ms. Hatch and her attorney to provide the presentation.

### Outcomes/Work Products:

- There have been no requests by people with disabilities to attend or present at a conference over the past quarter

### Attention Areas/Challenges

- Sharing information about available leadership training and opportunities for self-advocates to present on leadership topics at various venues

### Resources – What Helps to Make It Happen

- Council funds dedicated to conference funds
- Council member and Staff time to review applications and make arrangements as needed
- Support from other agencies/organizations

### Schedule

Project is on track:
Objective is achieved as the Council dedicates money each year to support conference attendance and presentations by self-advocates.

Jenny Hatch
of the *Jenny Hatch Justice Project*

## 2.4 Leadership Development for Families

Objective Goal **<u>Provide or support</u> at least one (1)** leadership development program for parents and family members **of people with developmental disabilities**

PIP Graduate Erin Rosenkoetter, Council Chair, Debra Parsons and PIP Coordinator, Bonnie Markham

### Progress

<u>Partners in Policymaking (PIP) Program Planning</u>

- April session on self-determination and family support was held in Boise
- May session was collaborating with agency leaders and graduation

<u>Parent Conference Funding</u>

- 2 requests were received for future conferences, however, none were funded during Quarter 3

### Outcomes/Work Products:

- PIP materials, curriculum, presentations and session information
- 25 Partners trained and graduated

### Attention Areas/Challenges

- Support for PIP participants to attend sessions

### Resources – What Helps to Make It Happen/What is Needed

- Council budget dedicated to conference funds
- Council budget dedicated to supporting PIP program
- Council staff time to plan for and conduct program

### Schedule

Project is on track: Objective is partially achieved when the Council dedicates money each year to support parents to attend conferences or training. Partners in Policymaking program completed as of May 2016 with follow-up to occur in next 5-Year plan.

## 2.5 Community Development

Objective Goal **Create and support a grassroots, diverse** coalition to build capacity through community development **in at least one (1) community**

### Progress

Developing Community in Caldwell

- 3 Community Dinners held in various sites across Canyon County
- 5 intentional listening conversations with community members
- 2 information meetings held at the Department of Health and Welfare with purpose of informing Dept. staff about barriers to accessing services for Spanish-speaking children/adults
- Collaborative presentation at local DDA provider to community members and service providers

### Outcomes:

- Learning about other groups working on community objectives
- Connections to more local organizations and community members
- Increased awareness for Caldwell community groups
- Building relationships for possible future collaboration

### Attention Areas/Challenges

- Identifying partners who are willing to look outside to make the entire community more welcoming for everyone

### Resources – What Helps to Make It Happen/What is Needed

- Staff time to be "on the ground" talking with community members
- Funding to support Community Connector work
- Referrals and connections to possible future partners

### Schedule

Objective may be achieved by the end of 5-year plan.

## 2.6 Council Member Leadership

### Objective Goal

Ensure that Council members get the support and training they need to fulfill their responsibilities under the law**, are provided easy-to-understand information, and participate in Council self-assessment each year.**

### Progress

Council Member Leadership

- April meeting consisted of presentation about potential topics to be chosen for the 5-Year plan and then adoption of ideas for 2016-2021 broad areas for 5-Year plan.
- One Council member graduated from Partners in Policymaking in May 2016 with a vast knowledge in leadership and working collaboratively with decision makers
- Three Partners in Policymaking graduates from the 2016 class and one from the 2010 class applied and were appointed by the Governor to serve on the Council

### Outcomes:

- Member understanding of key facts and trends that is necessary to improve the lives of people with developmental disabilities in Idaho
- Council member applications sent to Governor's office for approval

### Attention Areas/Challenges

- Members input on future leadership development activities
- Planning future asset-based member development activities

### Resources – What Helps to Make It Happen/What is Needed

- Members represent the Council in their local community
- Members engaged in meeting discussions
- Process to get member input on leadership development
- Staff time develop materials and provide support to members

### Schedule

Project is on track to achieve objective by the end of 5-year plan.

## 3.1 Inclusion and Awareness

Objective Goal Promote inclusion **by including people with disabilities in at least two non-disability community programs, organizations, activities, or media campaigns each year.**

### Progress

<u>Awareness Activities</u>

- Community Development project outreach in Caldwell/Canyon County

### Outcomes:

- Increased awareness of inclusion for Caldwell community groups and citizens

### Attention Areas/Challenges

- Measuring awareness, knowledge of principles of inclusion
- Identifying "non-disability" media campaigns
- Being aware of opportunities for individuals to be involved in non-disability organizations, programs

### Resources – What Helps to Make It Happen/What is Needed

- Information about non-disability organizations and programs
- Sharing opportunities for involvement with individuals with DD

### Schedule

Objective may be achieved by the end of 5-year plan.

## 3.2 Access to Information

Objective Goal Provide easy-to-understand information about Idaho's developmental disability service systems **through printed materials, social media, and a Council website**

Progress

Council Website Updates, Electronic Newsletter, and Facebook Activity

- Website announcements and Facebook posts included policy updates about the legislature and specific issues including Close the Gap
- White paper regarding ABLE Act drafted
- Summer eNewsletter under development

Outcomes:

- Facebook and Website postings
- Public awareness of Council projects and activities

Attention Areas/Challenges

- Measuring public awareness through Facebook activity
- Updating Frequently Asked Questions area of website
- Increase outreach to new people

Resources – What Helps to Make It Happen/What is Needed

- Staff time to create materials, reports
- Staff time to update website, post to Facebook page
- Staff time needed to develop and expand webpages and links to resources

Schedule

Project is on track to achieve objective by the end of 5-year plan.

## 4.1 Policy Involvement

Objective Goal Keep the Council involved in work on policy issues by **participating in meetings of the Consortium of Idahoans with Disabilities and other groups**

Progress

Testimony, Meetings, and Policy Discussions

- Monthly Consortium for Idahoans with Disabilities (CID) meetings
- Participation in workgroups: Children's Services Access and Family-Directed Services QA Committees, Secondary Transition Council, Community Care Advisory Council, Self-Direction Quality Assurance, CID Mental Health Oversight Committee

Outcomes:

- Work towards ABLE Act technical assistance and education legislation
- Provided written public comment on Administrative Rules Governing Residential Habilitation Agencies

Attention Areas/Challenges

- Development of plain language information for members and public
- Staff time for effective follow-up from meetings attended

Resources – What Helps to Make It Happen/What is Needed

- Staff time to attend meetings, develop materials, provide public comment
- Collaboration with CID members and DD Network partners
- Good relationships with various systems administration and staff

Schedule

Project is on track to achieve objective by the end of 5-year plan

## 4.2 Legislative Advocacy Training

Objective Goal **Work with partners to support annual** Disability Advocacy Day activities and legislative training **for individuals with DD, family members, and guardians.**

Progress

Disability Advocacy Day at the Capitol

- Event held in Feb 2016--Achieved

Legislative Advocacy Training

- Achieved during PIP and January Council meeting.

Outcomes:

- Outcomes achieved: ABLE Act information given to legislators

Attention Areas/Challenges

- Future opportunities for disability advocacy trainings and further training for individuals to provide testimony and/or meet with their elected officials

Resources – What Helps to Make It Happen/What is Needed

- Achieved during previous quarter

Schedule

Project is on track: Objective has been achieved each year the Council worked with partners to support legislative advocacy training and Disability Advocacy Day activities.

## 4.3 Council Policy Agenda

Objective Goal **<u>Support</u> Council members to** identify emerging issues and develop a yearly policy agenda **by <u>providing easy-to-understand information</u>**

Progress

<u>Policy Agenda – Issues Addressed</u>

- Presentation to Council of 2016 Final Legislative report at April Council meeting
- Draft and presentation of staffing proposal to Governor's office that requires JFAC approval of budget request (if approved position to begin in July 2017)
- Continued monitoring and support of Close the Gap/Medicaid Expansion efforts in Idaho

Outcomes:

- Stakeholders collaboration on Council policy agenda issues
- Meetings with Governor's office and other officials regarding staffing proposal

### Attention Areas/Challenges

- Council members and staff to monitor policy issues
- Policy workgroup (when needed)

### Resources – What Helps to Make It Happen/What is Needed

- Staff time to bring stakeholders together, draft recommendations from groups, legislation, or other policy, and educate policymakers
- Timely interaction with Council members to move forward with Council positions on emerging issues
- Communication with partner organizations
- Accurate drafting and dissemination of information on issues

### Schedule

Project is on track: Objective is achieved as the Council develops and implements a policy agenda each year.

## 4.4 Legislative Advocacy by Members

Objective Goal **Support Council members to** develop relationships with legislators and other policymakers

### Progress

Meetings with Policymakers

- Achieved during January Council meeting

### Outcomes:

- Policymakers received 2015 ICDD Annual Report in January 2016

### Council Attention Areas/Challenges

- Communicating about the Council, its positions, and policy agenda

### Resources – What Helps to Make It Happen/What is Needed

- Accurate information to share with Council members and elected officials

### Schedule

Project is on track: Objective is achieved as the Council members contact policymakers each year and share information about the Council and issues.

# Cultural Competence Training

## Background Information:

Sonya Rosario, Director of the Women of Color Alliance will be providing the Council members and guests with an overview and understanding of cultural differences that will inform the Council's work within the 5-Year Plan. The purpose of the training is to meet five year planning requirements of being a more culturally sensitive organization. "Cultural competent/sensitive" means that the Council is committed to getting to know individuals, committed to understanding their unique life circumstances and learning as much as possible about the person's support systems both within and outside the family. The Council will commit to recognize how the person's culture may have influence on his/her personal goals and how that may relate to how we work on projects here at the Council.

Because this is a process that develops over time, this will be the first of a series of trainings that will be provided to Council members in order to achieve compliance with the Administration on Intellectual and Developmental Disabilities (AIDD) mandate of culturally and linguistically competent work for all Councils in every state and territory across the United States.

## Recommended Action:

Listen, actively participate, learn and ask questions.

## Notes:

## Idaho Council on Developmental Disabilities

# Cultural Competence Homework

On Friday, July 22nd, Sonya Rosario, Director of the Women of Color Alliance will be providing the Council members and guests with an overview and understanding of cultural differences that will inform the Council's work within the 5-Year Plan. The purpose of the training is to meet five year planning requirements of being a more culturally sensitive organization. "Cultural competent/sensitive" means that the Council is committed to getting to know individuals, committed to understanding their unique life circumstances and learning as much as possible about the person's support systems both within and outside the family. The Council will commit to recognize how the person's culture may have influence on his/her personal goals and how that may relate to how we work on projects here at the Council.

Because this is a process that develops over time, this will be the first of a series of trainings that will be provided to Council members in order to achieve compliance with the Administration on Intellectual and Developmental Disabilities (AIDD) mandate of culturally and linguistically competent work for all Councils in every state and territory across the United States. In order to prepare for the training, we ask that each of you read the first article and watch the second two videos. We ask that everyone come with an open mind and a hunger for learning as we embark on the journey of becoming a more culturally and linguistically sensitive organization.

1. The Invisible Knapsack
https://www.deanza.edu/faculty/lewisjulie/White%20Priviledge%20Unpacking%20the%20Invisible%20Knapsack.pdf

2. The Danger of a Single Story
https://www.ted.com/talks/chimamanda_adichie_the_danger_of_a_single_story

3. How I Learned To Stop Worrying and Start Loving Discussing Race
https://www.youtube.com/watch?v=MbdxeFcQtaU

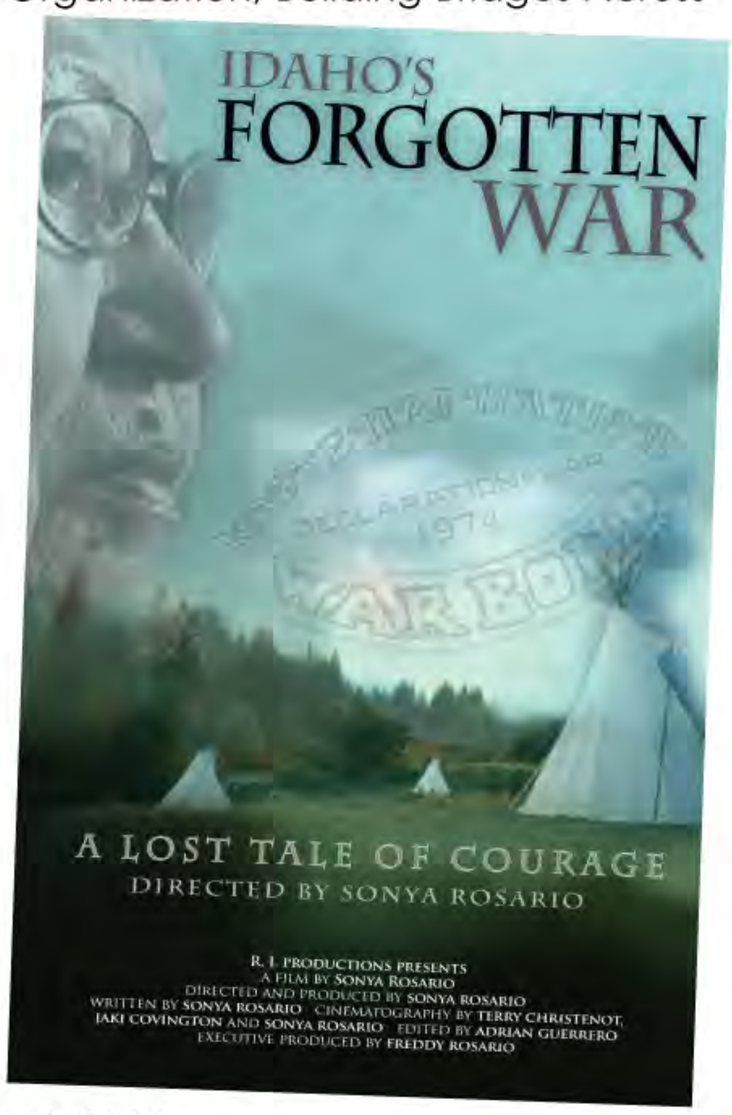
*"When you love and are committed to community you will make change happen"*

*Sonya Rosario*

## ACTIVIST

Dedicated to working with and advancing the progress of women and girls who are; African American, Latina, Native and Immigrant Women and to break down myths and barriers that women have about each other.

Founder WOCA, Women of Color Alliance, Statewide Organization; Building Bridges Across Cultural Alliances, Gender and Race Equality, 2001




## PRODUCER, DIRECTOR & FILMMAKER

**"Idaho's Forgotten War", 2009**

*The film profiles the courage and faith of 67 Idaho Kootenai people and the extraordinary woman, Amy Trice, who declared war on the United States government on September 20,1974. The true story about the people and the woman, whose commitment would not waiver, and her courageous spirit that lead a bloodless war, which helped the Kootenai people rise out of the ashes to become a prosperous Indian Nation.* **www.idahosforgottenwar.com**

**"The Historical Impact of the "S" Word; from One Generation to the Next, 2002**

*A film created by the passion to make a wrong, a right. Ignored by the Idaho State Legislature, several Native sisters came to Sonya to assist them in rallying the women of Idaho to support the removal of the word "squaw" from Idaho land places. The powerful film, reveals the human side of the story told by Native women who give testimonials of the historical and traumatic impact of this word and it's meaning to them.*

## ACCOMPLISHMENTS

Awarded: The Legacy of Leadership Award, Spelman College, 2007
Northwest Community Development Institute, Dept of Commerce, Certificate of Achievement, 2006
Idaho Statesman Newspaper, "Woman Making Change in Idaho" 2004
Represented WOCA, Civil Society Luncheon, United Nations for Kofi Annan, Secretary General, 2003
Women's Campaign School at Yale University, New Haven, CT. Certificate of Achievement, 2003
Boise State University Recognition, "Women Making History," 2000

## PUBLISHED POET

"Color de Mujer", Idaho Spanish Publication, 2002
Manifestaciones Mueres Pasion", Idaho Spanish Publication, 2001
Anthology of Latina Writers - Communal Feminisms; Chicanas, Chilenas, and Cultural Exile by Dr. Gabriella Gutiãaerrez y Muhs, Seattle University Publication, 2007


# Sonya Rosario

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